

California's
Caregiver Resource Center System

ANNUAL REPORT

*The Comprehensive Act for Families and Caregivers
of Brain-Impaired Adults*

**Chapter 1658, Statutes of 1984, as amended by Chapter 775,
Statutes of 1988 and Chapter 7, W&I code, Section 4362 et al., 1992**



July 1, 2001 through June 30, 2002

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ANNUAL REPORT

FISCAL YEAR 2001-2002

*The Comprehensive Act for Families and Caregivers
of Brain-Impaired Adults*

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EXECUTIVE SUMMARY

This report addresses the progress of the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*¹ between July 1, 2001 and June 30, 2002. This time period marks the seventeenth year of implementation of this statute demonstrating California's commitment to serving family caregivers. The report profiles family caregivers and the adults with cognitive impairment for whom they care and includes: 1) the cost and amount of each service provided; 2) an assessment of the nature and extent of the demand for services which provide respite; 3) an analysis of the program in deterring the institutionalization of adults with cognitive impairment; and 4) recommendations for ensuring that unmet needs of cognitively impaired persons and their families are identified and addressed with appropriate programs and services.

The Department of Mental Health (DMH) established the Caregiver Resource Centers (CRCs) statewide program in 1984. The CRCs were legislatively mandated to assist families who provide long-term care for loved ones afflicted with Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury, and other chronic or degenerative cognitive disorders that strike adults. At the end of Fiscal Year (FY) 1988-89, eleven non-profit centers were designated, covering all geographic regions in California. Additionally, the law established a Statewide Resources Consultant (SRC) to operate a statewide information and technical assistance clearinghouse on cognitive impairment, and assist the DMH by providing consultation, training, research, technical, and program assistance to the CRCs.

The total contract awarded to the eleven resource center sites and the SRC was \$11,747,000 in FY 2001-02, representing a reduction of \$500,000 (*or 4%*) from FY 2000-01. During FY 2001-02, the CRCs also received funding from the new National Family Caregiver Support Program (NFCSP) administered through California's Department of Aging and thirty-three Area Agencies on Aging. Utilizing NFCSP funds, the CRC system provided additional services to caregivers in the following areas: gaining access to supportive services; information about available services; individual counseling; organization of support groups; caregiving training; respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and supplemental services to complement the care provided by the caregivers.²

During fiscal year 2001-02:

- The total number of individuals receiving at least one CRC service increased from FY 2000-01 (from 14,201 to 14,475) while the number of families receiving CRC respite assistance fell from 2,206 to 1,841 over the same period.
- Most family caregivers received an average of 5.1 hours of caregiver support services³ beyond basic information and comprehensive assessment, excluding respite assistance.

¹ Chapter 1658, Statutes of 1984, as amended by Chapter 775, Statutes of 1988 and Chapter 7, W& I Code, Section 4362, et al., 1992.

² This report only includes service figures for Chapter 1658 funds, i.e. detailed service data on NFCSP funds are not included in this report.

³ Includes one or more of the following: family consultation, counseling, legal assistance, support group, caregiver retreat, education/training, and psychoeducational group.

- A total of 6,526 family caregivers completed the intake process, contacting a CRC for the first time. *Fifty percent* of those completing intake went on to receive additional CRC services.
- The annual expenditure for respite care voucher services at the 11 CRCs was \$2,905,866 or an average of \$3,383 per family caregiver who received respite per year. The average monthly cost per family caregiver was \$300, of which \$282 was provided by the CRCs. The average monthly cost for a Medi-Cal patient (\$3,393 in FY 2001) in a California skilled nursing facility is over *11 times* the average monthly cost of CRC respite services. The average monthly private pay nursing home cost is over *14 times* (\$4,322 in 2002) the average monthly cost of CRC respite services.
- **Respite is a primary need for caregivers. The average time clients wait for CRC respite assistance is 20 months. At the end of FY 2000-01, 4,241 family caregivers were on respite waiting lists at CRCs in California.**

Key findings from the CRC statewide assessment database⁴ are as follows:

- The typical caregiver is 61 years old. *Fifty percent* of caregivers are 60 years of age or older; *twenty-two percent* are at least 75 years old or older.
- The family caregiver is most likely to be a female (74%), typically a wife or daughter.
- Caregivers provide an average of 11.6 hours of care per day – more than a full-time job.
- Caregivers receive only an average of 1.7 hours of help per day from family or friends. Close to 7 out of 10 (68%) caregivers feel they receive “far less” and “somewhat less” help from family or friends than they need.
- One-third (33%) of caregivers reported feeling “depressed,” while 58% were scored as “depressed” using the Center for Epidemiological Studies Depression Scale (CES-D). Overall, 50% report high burden levels, and 42% of the caregivers say their physical health is now worse than five years ago.

The need for **basic information continued to be the number one need expressed by caregivers at intake** followed by respite care and emotional support. For caregivers who went on to receive the more in-depth CRC assessment, these same key needs were reported. While there are some difficult cases where it may not be possible for family caregivers to keep their loved ones at home, information and support services help to deter the institutionalization of the care receiver.

⁴ Data are from the CRC Uniform Assessment Database 2001. See the Methodology section for more detailed information.

The following recommendations address the needs of California's caregivers of cognitively impaired adults:

1. Increase the number of caregivers receiving core CRC services through community-based collaborations and widely disseminated information and education campaigns targeting underserved caregivers, particularly minority and rural caregivers.
2. Promote public policy that advances the consumer-directed model of care for all caregivers and care receivers and supports the prevention, diagnosis, treatment, and cure of brain impairing conditions.
3. Improve assistance to working and isolated caregivers via technology, e.g., increase the number of caregivers using the Link2Care.
4. Explore establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.
5. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term care options for care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
6. Identify viable program options for traumatic brain injury (TBI) caregivers and their loved ones.
7. Carry out CRC research to: 1) measure and analyze the impact of cognitive disorders on family and caregiver well being, and (2) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Enhance local partnerships with AAAs to expand family consultations, counseling, and respite services to caregivers using National Family Caregiver Support Program funds.

ISSUE

Each year the number of informal caregivers – those who provide care without pay – increases in California. Current estimates indicate approximately 3 million informal caregivers are providing care to a family member or friend in the Golden State.⁵ Although the primary needs of all caregivers are similar (e.g., the need for basic information, respite care, and emotional support), caregivers of adults with cognitive impairments have special needs. In fact the cognitive, behavioral, and psychological changes associated with brain impairment in individuals with Alzheimer's disease, stroke, Parkinson's disease, Huntington's disease, and traumatic brain injury often result in difficulties with activities of daily living (e.g., bathing, eating, and dressing), memory functions, and emotional and mental well-being. In turn, these difficulties promote tremendous physical and emotional burnout, financial stress, and self-sacrifice among family caregivers, exacting enormous tolls on families, communities, and society. To cope, caregivers require a range of caregiving services designed to provide support throughout the caregiving experience.

To address the needs of caregivers of adults with cognitive impairments, a population traditionally outside the mainstream service delivery system, Chapter 1658, Statutes of 1984, was enacted. This legislation, which created statewide support services for the growing population of family caregivers caring for individuals with cognitive impairment, identified the informal caregiver as the "client." In particular, the legislation provided critical support for caregivers of adults with Alzheimer's, Parkinson's, stroke and other cognitive diseases and disorders by addressing family caregivers shared common concerns and challenges: isolation, emotional distress, lack of information and community resources, and drastic changes in family roles.

Chapter 1658 legislation, as amended by Chapter 775, 1988, and Chapter 7, W&I Code, Section 4362 et al., 1992 and known as the ***Comprehensive Act for Families and Caregivers of Brain-Impaired Adults***, directed the Department of Mental Health (DMH) to establish a statewide system of Caregiver Resource Centers (CRCs) in California. The centers were designed to facilitate a single point of entry for caregivers within each CRC service region with appropriate programs and services for families and caregivers of adults with cognitive impairment.

To promote the goals of the legislation, the law also established a Statewide Resources Consultant (SRC) to do the following: serve as the centralized information and technical assistance clearinghouse on caregiving and cognitive impairment; provide consultation, training and technical assistance to the CRCs; conduct conferences, social policy research, and training programs to enhance the quality of care and treatment of brain-impaired adults; assist the State in coordinating with other state initiatives; and aid the DMH in evaluating the effectiveness of the CRC system.

⁵ Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs* 18, 182-188.

To appropriately assess the effectiveness of the CRCs, the enabling legislation requires the Department, in consultation with the SRC, to report annually to the Legislature on the following:

- 1) The costs and amount of each type of service provided.
- 2) An assessment of the nature and extent of the demand for services, which provide respite, and an evaluation of their success in meeting this demand.
- 3) An analysis of the program in deterring the institutionalization of brain-impaired adults, allowing caregivers to maintain a normal routine and promoting the continuance of quality care for adults with cognitive impairment.
- 4) Recommendations for ensuring that unmet needs of cognitive-impaired persons and their families are identified and addressed with appropriate programs and services.

This report addresses these requirements and provides information on the eleven CRCs for the period July 1, 2001 through June 30, 2002.

BACKGROUND

History

The CRC system began as a grass roots community effort more than a quarter century ago to address the myriad of problems associated with adult onset cognitive disorders. The compelling story of one San Francisco woman caring for her husband with Alzheimer's disease alerted policy makers and service providers to the scarcity of available residential placements and the lack of supportive services for family caregivers.

A San Francisco task force was convened in 1976 to investigate the chronic care problems of middle-income Americans with irreversible cognitive impairment. Two years later, DMH awarded a special grant to the task force, then known as the Family Survival Project (later changed to *Family Caregiver Alliance*), to conduct a needs assessment of the San Francisco community to determine the number of adults with cognitive impairments and available services.

In 1980, under Chapter 1058, Statute of 1979, the DMH contracted with Family Caregiver Alliance to establish a pilot program to test the effectiveness of services to families and caregivers of adults with cognitive impairment. The project confirmed the package of core services developed in the pilot program were successful in assisting families and caregivers of persons with all forms of adult-onset cognitive impairment in coping with their caregiving responsibilities and avoiding or delaying the need for skilled nursing or institutional care of the care receiver.

In 1984, Chapter 1658 (AB 2913, Agnos) was signed by the Governor which: 1) phased-in development of resource centers, based on the successful model of Family Caregiver Alliance's pilot program, in each major geographic region of the State that, together, would provide a single-entry information network; and 2) established the SRC role under contract to the State to implement aspects of the new law that were statewide in nature.

Phasing-In of CRC Sites

Implementation began in FY 1984-85 with continuation of Family Caregiver Alliance as the first CRC serving the greater San Francisco Bay Area. DMH also awarded the contract for the SRC to Family Caregiver Alliance in 1985. All eleven regional CRC sites were operational by 1989. **In FY 2001-02, the total contract award to the eleven resource center sites and the SRC was \$11,747,000.00, representing a reduction of \$500,000 (or 4%) from FY 2000-01.** See Appendix A, Site Distribution List, for a listing of site names, host agencies, and counties covered.

Overview

Caregivers of adults with cognitive impairment face daunting and complex problems, which dramatically alter their physical, emotional, and financial health. To address these multi-faceted needs, the CRCs provide a single point of entry for families. Respite, counseling and emotional support, education, and training are provided to caregivers from the moment of first contact until the family no longer requires assistance, often many months and years later. Of equal importance, CRCs work closely with a full range of community organizations and services to effectively address the diverse needs of the caregivers.

OBJECTIVES

The service components provided by the resource centers include the following:

- **Information, advice, and referral;**
- **Assessment of caregiver needs;**
- **Long-term care planning and consultation;**
- **Legal and financial consultation;**
- **Mental health interventions** (such as counseling, support groups and psychoeducational groups);
- **Education and training programs;** and
- **Respite care services** through the flexible and creative use of local resources including: home care, adult day care services; foster and group care; transportation; and temporary placement in a residential facility.

Additionally, CRCs are mandated to:

- Provide centralized access to information about, and referrals to, local, state, and federal programs;
- Coordinate with other organizations serving adults with cognitive impairment, their families and caregivers;
- Assist in the identification and documentation of service needs;
- Promote the development of necessary community programs regionally; and
- Cooperate with the SRC and the DMH in the implementation of this program.

As required under the law, the DMH also maintains a contract with the SRC at Family Caregiver Alliance to:

- Serve as the Statewide Information and Technical Assistance Clearinghouse on adult-onset cognitive impairment and caregiving issues;
- Provide coordination with other statewide organizations, which serve adults with cognitive impairment, their families and caregivers;
- Develop and conduct training appropriate for families, caregivers, service professionals, advocacy and self-help family and caregiver support organizations; and educational institutions;
- Conduct conferences to assist families, caregivers, service professionals, advocacy organizations, educational institutions, business associations, community groups, and the general public;
- Assist in identifying and securing increased federal financial participation and third-party reimbursement;
- Conduct social policy research;
- Assist in data collection; epidemiological research; and development of uniform terminology and data collection;
- Assist the DMH in establishing criteria for and in selecting the resource centers; and
- Provide technical assistance and consultation to the resource centers for service and program development.

METHODOLOGY

Information and data were collected for this report from three sources: 1) CRC quarterly data collection on caregivers, care receivers, services and expenditures via the CRC uniform Services Automation System; 2) CRC Semi-annual Progress Reports; and 3) CRC uniform caregiver assessment data.

1. ***CRC Services Automation System*** and ***Caller/Caregiver Provider Tracking System (CCPTS)*** include data collection reporting requirements on all clients served, date of service, service mix, and case status. Major data components used in this report include:
 - a. **All individuals completing the CRC intake process** (e.g., the total number of callers, caller ethnicity and a summary of the callers' identified needs);
 - b. **The number of family caregivers served** and average service mix during the fiscal year;
 - c. **The units of service** (i.e., amount of service) **for each service** provided to family caregivers during the fiscal year;
 - d. **Expenditures for voucher services** as reported in the CRC Services Automation System; and
 - e. **Co-payments for respite services** paid by family caregivers.
2. ***Semi-annual Progress Reports*** include CRC progress on staffing and administrative functions; the documentation of any new unmet needs identified regionally; and activities and accomplishments in three strategic plan objectives.
3. ***Family caregiver assessment data*** are obtained using a uniform, comprehensive assessment instrument to determine the well being of family caregivers who contact the CRCs for help beyond basic information. CRC uniform assessment data from the 2001 calendar year is presented in the Findings Section.

FINDINGS

This section of the report provides findings from all three key sources of information to present a detailed and accurate description of caregivers served by the CRCs, the persons they care for, and the services provided to these individuals through the CRCs. First, a descriptive profile of care receivers and caregivers is presented. Second, findings, as specified in the legislation, addressing the cost and amount of services provided, the demand for respite care, the effectiveness of the program in delaying or deterring institutionalization, and the identification of unmet needs and service gaps for care receivers and their family caregivers in California are reported (Tables and Figures used for this report are presented on pages 23-48). Last, an outline of the CRC System Strategic Plan Goals and achievements are presented with recommendations to meet caregiver needs for FY 2002-2003.

Profile of Care Receivers and Family Caregivers⁶

A. Selected Care Receiver Characteristics:

Care receivers are typically older, ranging in age from 18 to 104 years old, with an average age of 75. *Eighty-four percent* are at least 65 years of age; *65%* are 75 years of age and older; and *23%* are at least age 85. *Eighty-eight percent* of care receivers are age 60 and older.

Care receivers are more likely to be female (*55%*) than male (*45%*). They mainly live with their spouse only (*49%*), or with their spouse and/or others (*34%*). Proportionately few care receivers live alone (*10%*) or in nursing homes (*1%*) when the caregiver first calls the CRC for assistance.

The median household income range for the care receiver population in 2001 was between \$30,000 and \$35,999, significantly below \$47,262 – the median income in California in 2001.⁷

Sixty-seven percent of care receivers have a dementing illness, principally Alzheimer's disease (*30%*), but also Parkinson's disease (*10%*), Huntington's disease (*3%*), and other dementias/degenerative diseases (*24%*). *Twenty-one percent* had a stroke, *4%* are traumatic brain injury survivors, and *2%* have brain tumors or other non-degenerative disorders. The great majority of care receivers (*88%*) have a confirmed diagnosis.

Thirty-six percent of care receivers experienced the onset of disease/disorder within the range of three to ten years. *Eleven percent* of the population has lived with their cognitive disease/disorder for 11 years or longer.

Thirty-six percent of the care receivers have out-of-pocket health care expenses. *Fifty percent* are enrolled in a health maintenance organization (HMO).

⁶ CRC Uniform Assessment Database 2001 (N = 3,476 family caregivers).

⁷ U.S. Census Bureau, Current Population Survey, 2000, 2001, and 2002 Annual Demographic Supplements.

Problem Behaviors Associated with Brain Impairment:

These care receivers have strikingly heavy care needs. As reported by their caregivers, they average eight memory and behavior problems, commonly related to the individual's cognitive deficits (e.g., communication, concentration), and nine functional problems related to inability to perform daily tasks (e.g., bathing, feeding, dressing; using the telephone, and performing chores).

Slightly more than half (54%) of care receivers are unable to perform three to five activities of daily living (ADLs) and 31% cannot perform one or two ADLs. Approximately seven in ten (70%) cannot be left alone and need constant supervision. Another 41% wake their caregiver at night, and 48% are incontinent.

B. Selected Caregiver Characteristics:

The typical caregiver served at California's CRCs is a 61-year old female who has been caring for her husband with Alzheimer's disease for one to two years.

Caregivers are predominantly female (74%), and range in age from 20 to 93 years with an average age of 61. Fifty percent of the caregivers are 60 years of age or older. Twenty-two percent are 75 years of age and older. Twenty-three percent are between the ages of 36-50 years.

Caregivers served by CRCs are typically spouses (47%), while 42% are adult children and 11% have another relationship to the care receiver.

Family caregivers are most likely to identify themselves as the "primary" caregiver (96%) and to live with the care receiver (79%).

The majority of family caregivers served by the CRCs are white (79%), 9% are Hispanic, 7% are African American, 3% are Asian/Pacific Islander, and 2% are reported as other ethnic groups.

Over half (54%) the caregivers under the age of 65 also work outside the home, either in full-time (40%) or part-time (15%) jobs.

Caregiver Well-Being:

Depression is a serious problem for family caregivers. Nearly six in ten (58%) CRC family caregivers show clinical symptoms of depression.⁸ Caregivers generally report high stress due to their caregiving situation, irrespective of their care receiver's specific diagnosis. Approximately one-third (33%) of caregivers self-report feeling "depressed." Overall, about 50% of caregivers report burden of care that ranges from "quite a bit" to "extreme," 66% report significant health problems, and 42% of the caregivers say their physical health is now worse than five years ago.

Caregiver Social Support:

Family caregivers served by CRCs report that they provide an average of 81 hours of care a week to their care receiver, or an average of about 11.6 hours per day. By comparison, these caregivers receive only 12.0 hours per week (or 1.7 hours per day) of help from family and

⁸ As evidenced by scores of 16 or higher on the Center for Epidemiological Studies Depression Scale (CES-D).

friends in the care of their relative. Typically, the "informal support" the caregiver receives from his/her own family and friends includes respite, housekeeping, grocery shopping, meals, personal care, and/or managing financial/legal issues.

Caregiver Service Needs:

The greatest caregiver needs, reported by caregivers, at intake, were for general information/orientation (73%), respite care (71%), and emotional support (70%). *Twenty-six percent* needed assistance with managing the care receiver's behavioral problems and 26% needed legal assistance.

Evaluation Components

The following findings address the requirements of Chapter 1658, as amended, to report on the effectiveness of the CRCs specific to:

1. The costs and amount of each service provided.

CRCs provide a range of services and service options to family caregivers. Services are individually tailored to meet the needs of each caregiver. For many, basic information is enough to meet their immediate needs, while others require further problem-solving, emotional support, or practical help with legal matters or other long-term care concerns.

The top four CRC services⁹ used by family caregivers (in rank order) include: **1) family consultation; 2) follow-up information and referral; 3) in-home respite assistance; and 4) support group** (Figure 1).

The majority of family caregivers (51%) used one service only (beyond intake and assessment) during the fiscal year. The proportion of family caregivers utilizing two services increased to 37% from 31% in fiscal year 2000-01, and the proportion of family clients using three or more services decreased to 14% from 16% in FY 2000-01 (Figure 2).

During FY 2001-02, **a total of 14,475 family caregivers utilized one or more services** at the eleven CRC sites in California, *a 2% increase* over the previous year (FY 2000-01). Of these, **11,903 (82%) received core CRC services** (i.e., services beyond just information or assessment). The average service use per client across all CRC core services was 28.9 hours during the fiscal year. However, caregivers using CRC respite substantially skewed this average. When respite users are removed, family caregivers received an average of 5.1 hours of service per year (Table 1). **A total of 9,766 family caregivers had active cases¹⁰** during at least some portion of FY 2001-02, *a 6% increase* over the previous fiscal year (Table 5). Tables 2 and 3 show the total number of family caregivers receiving CRC services by service type, and the total amount of service used, respectively. Table 4 presents the average amount of

⁹ Excludes those caregivers completing only an intake and/or an assessment or reassessment.

¹⁰ The active caseload total excludes caregivers who receive only intake and/or follow-up information and referral. Caregivers with active cases receive an initial assessment and continue to receive routine reassessments, in addition to other CRC services.

service used per family caregiver, by service during FY 2001-02. Table 6 and Figure 3 show voucher service expenditures.

A total of 6,526 family caregivers¹¹ completed the intake process across the eleven CRC sites, *a 4% increase* over the previous fiscal year. Additionally, during this fiscal period, **4,857 caregivers received an average of 1.1 hours of follow-up information** during the current fiscal year (Tables 2 and 4).

A total of **3,865 caregivers completed a CRC in-home assessment** to determine their needs for further services, measure their stress and burden, and to develop a care plan. Approximately half (50%) of caregivers completing intake went on to be assessed. The number of in-home assessments conducted during FY 2001-02 increased by 13% over the number of assessments conducted during FY 2000-01 (Tables 2 and 5b).

A total of **3,990 family caregivers received a reassessment¹²** conducted at six-month intervals to examine change in caregiver well being over time (Table 2). The number of reassessments performed during this fiscal year decreased overall by 3% from the previous fiscal year.

A total of **10,243 family caregivers received an average of 2.3 hours of family consultation service** each during the fiscal year (Tables 2 and 4). Family consultations offer some combination of information and advice, planning and problem-solving consultation, and/or emotional support and intervention with existing service systems.

A total of **12,922 family caregivers and professionals received family-focused education and training** (Table 10). These typically small group events provide practical information to better enable families to understand cognitive disorders, manage daily care, cope with stress, and plan for long-term care.

A total of 921 caregivers received an average of 8.2 hours of emotional support and information exchange through attendance at CRC-sponsored support groups. A total of **268 caregivers attended psychoeducational groups**, offered by ten CRCs. Caregivers received an average of 17 hours of this service (Tables 2 and 4). These structured sequential class series combine training on practical coping skills, self-care and relaxation techniques.

A total of 301 caregivers received an average of 4.5 hours of **individual counseling** to offer more in-depth emotional support and mental health intervention beyond family consultation. For caregivers who received counseling from subcontracted therapists (e.g., by voucher) the average cost per client was about \$259 for four one-hour sessions (Tables 2, 4, and 6).

A total of 398 caregivers received an average of 1.1 hours of **legal/financial consultation** with a CRC contract attorney as part of the long-term care planning process. The average CRC cost per family client for this service was \$107 (Tables 2, 4, and 6). Regional variations in legal

¹¹ Another 1,766 service providers and members of the general public also completed a CRC intake during FY 2001-02 (Table 13).

¹² Another 3,649 caregivers received a “status change” in cases where the adult with brain impairment or caregiver had died or the caregiver had moved out of the CRC region (Table 2).

consultation costs at CRCs are shown in Figure 4.

A total of 1,841 family caregivers received CRC **respite assistance**, receiving an average of about 329.6 hours of respite during the year (Tables 2 and 4). The proportion of family caregivers receiving respite services decreased 17% this fiscal year, compared to fiscal year 2000-01, due in part to the cut of half a million dollars from the CRC System budget. Respite services, while delivered to the care receiver, are designed primarily to benefit the family caregiver by relieving the caregiver's constant care responsibilities. Utilization of respite varied from site to site based on caregiver need and the availability of funds and services (Figures 5-8).

2. An assessment of the nature and extent of the demand for services providing respite and an evaluation of their success in meeting this demand.

Chapter 1658, as amended, Section 4362.5(c), defines respite as:

"Substitute care or supervision in support of the caregiver for the purposes of providing relief from the stresses of constant care provision and so as to enable the caregiver to pursue a normal routine and responsibilities. Respite care may be provided in the home or in an out-of-home setting, such as day care centers or short-term placements in inpatient facilities."

Caregivers, who completed the uniform assessment process, reported the need for respite care as slightly greater than the need for emotional help (71% and 70%, respectively). This level of need is related to the strain these families experience:

- *Twenty-eight percent* of caregivers feel moderately burdened, 32% feel burdened quite a bit, and 18% feel extremely burdened; 13% percent indicate that they felt 'a little' burdened.
- *Twenty-eight percent* of caregivers rate their overall health as fair to poor, and 42% say their physical health is now worse than five years ago.
- **Caregiver depression is high: 58% of caregivers exhibit symptoms of clinical depression.**

The consistently high levels of caregiver burden, fair to poor physical health, and depression suggest that caregivers across the state continue to be a high-risk population. Severe depression may impair the family member's ability to provide continued care for a care receiver. Respite care is greatly needed by caregivers to break from oftentimes 24-hour care demands.

By the end of FY 2001-02, the eleven CRCs provided a total of 283,115 hours of respite care to 1,841 families (Tables 8, Figure 5). About 859 families, on average, received respite services each month at the eleven CRCs (or 78 families per site per month).

- On average, caregivers received six hours of respite care per week (Table 8).
- Among caregivers using in-home respite, 54% used the “direct pay” in-home respite; fewer (51%) used the vendor in-home respite option.¹³
- Because of the lower cost of "direct pay" in-home respite, **caregivers utilizing the direct-pay option received approximately twice as much service**—(159 hours vs. 85 hours) on average, per family caregiver (Figure 8).
- The annual expenditure for respite care voucher services at the eleven CRCs was \$2,905,866 or an average of \$3,383 per family caregiver per year (Table 9).
- The total expenditures for CRC respite care services *including family caregiver share of cost* was \$3,212,812 or \$3,601 per family caregiver per year (Table 9).
- On average, over **three quarters (76%) of families who received respite services contributed toward this care through co-payments**, based on family income and household size (Table 9).
- Annual co-payment income collected from families amounted to \$306,946 or 10 percent of the total cost, thereby reducing the total costs to the State (Table 9).
- **The average monthly cost of CRC respite voucher services per family caregiver was \$300**; \$282 was provided by the CRCs. Family caregivers contributed, on average, an \$18 co-payment (Table 9).

The average cost per family caregiver per month varied from region to region, based on budget allocations for respite, availability of community respite options, and amount of respite care provided per family. As of January 1, 2002, all caregivers new to receiving respite are eligible for a one-year-only \$3,600 respite benefit in order to provide respite to the large number of people on the respite waiting list. A total of 4,241 California family caregivers remained on CRC respite lists at the end of the FY 2001-02 (Table 2). Since demand for respite services continues to exceed the resources available at CRCs, **family caregivers in need of respite care waited an average of 20 months on a respite waiting list before receiving CRC respite assistance** (Table 3).

Throughout the fiscal year, a total of 2,824 cases were closed. **Of cases closed providing a reason, one-third were closed due to the care receiver’s death (39%); in 6% of the cases, the caregiver died or moved. A total of 495 family caregivers reported placing their relative in**

¹³ Some families use more than one type of respite. Therefore, the sum of the total percentages for individual types of respite exceeds 100 percent.

a residential facility (primarily in a skilled nursing facility) during FY 2001-01 (Table 5, Figures 9 and 10). Since caregivers are on CRC respite waiting lists for an average of 20 months, invariably some caregivers experience the death or institutionalization of care receivers prior to receiving respite services.

It is important to note that respite services alone may not meet the multi-faceted needs of family caregivers. At the time of assessment, approximately seven in ten families indicated a need for emotional support. CRCs work to integrate mental health interventions and ongoing contact with family caregivers to ensure a complementary package of supportive services. For the caregivers on respite waiting lists, these other CRC services can help bolster families and help them cope with the burden of care.

3. An analysis of the program in deterring the institutionalization of cognitively impaired adults, allowing caregivers to maintain a normal routine and promoting the continuance of quality care for adults with cognitive impairment.

Maintaining a loved one at home with a cognitive impairment/disorder can be extremely difficult especially when the cognitive-impaired adult experiences increased confusion, which often leads to paranoia and difficult behaviors. Take the examples of Mr. K and Ms. L:

Mr. K came to Southern Caregiver Resource Center after reading an article in the newspaper about the CRC. He is a 52 year-old man caring for his 50 year-old wife, who was diagnosed with Multiple Sclerosis in 1992. Mr. & Mrs. K have been married for over 20 years and have a 17 year-old son who is preparing to attend college. Mr. K works full time but has altered his schedule to spend one workday each week with his family. Their son is planning on living at home while attending college to assist with his mother's care.

The K's had been on Southern CRC's respite wait list for about 1 ½ years before beginning respite services that will continue for 1 year. They are currently receiving about 4 hours a week of assistance through a home care agency. The majority of the assistance for Mrs. K is devoted to personal care and companionship. Mr. K explains that the respite services could not have come at a better time, because Mrs. K continues to decline and is now confined to her bed. Mr. K expressed his deep appreciation for the support and "psychological boost" the respite has provided for him and his son.

Ms. L and her mother always had a very close relationship. So when Ms. L's mother's health fell apart ten years ago, Ms. L left her highly successful career in Cincinnati to move to California to be at her mother's side. Sadly, she came home to find a very sick, bedridden and depressed woman, and a house in great disrepair. In response, Ms. L swung into action to rescue her mother from this miserable condition. Little did she know that her mother was in the beginning stages of Alzheimer's disease and that her caregiving journey would last ten years.

"Caregiving made me vulnerable because the more intensely I cared for her, the more I had to forget myself.... It was a big sacrifice -- my self took a beating!" Ms. L commented. "Del Mar Caregiver Resource Center made a huge difference! Two Family Consultants came to the house ...and set out to do everything they could to help me. Del Mar CRC honored what I was

doing.... and introduced me to a community of other caregivers. They directed me to Safe Care, an adult day care center...where dynamic, compassionate and patient caregivers gave me relief. Most importantly, Del Mar CRC emphasized taking care of me, not just Mom.” Ms. L’s caregiving years were not easy, but she says she has no regrets. “Truly loving someone, being aware of beauty and keeping the senses alive helps you appreciate each breath. Some people get that from studying Zen or reading books, I learned it from taking care of my mother.”

CRCs provide emotional and practical support to caregivers, allowing them to better cope with the responsibilities and burdens of caring for their loved one at home. While immediate intervention helps families find alternatives to the institutionalization of a relative, ongoing support is also provided. Throughout the caregiving process, CRC staff members maintain regular contact with families receiving respite care in order to ensure that quality care is being provided. In addition, feedback from caregiver clients is used to improve services and meet the changing needs of family caregivers.

As was shown with Mr. K and Ms. L, families must be informed about all their options and they must be given support in a time of crisis. Without help, caregivers are at risk of becoming depressed or ill themselves, leaving two people in need instead of one. This risk is even more acute, if the caregiver is elderly. CRC data show that most caregivers contacting CRCs are middle age or older and have modest incomes. Given these demographics, caregivers served by the CRCs are likely to have long-term care needs but limited ability to pay for them. Without affordable community-based care, many families needing long-term care will resort to Medi-Cal to pay the costs.

The average monthly cost for a Medi-Cal patient in a California skilled nursing facility was \$3,393 in fiscal year 2001 — over 11 times the \$300 average monthly cost of CRC respite services. Private pay nursing homes cost residents over 14 times (\$4,322 per month) the cost of CRC respite (See Table 7 for Medi-Cal and private pay rate references).

As previously noted, during FY 2001-02, CRCs spent \$2,905,866 providing respite assistance to a total of 1,841 California caregivers. **If each of these family caregivers were forced to place their relative in Medi-Cal nursing homes, the cost would be staggering – over \$76 million per year.¹⁴ Clearly, even if CRC respite services help only some portion of family caregivers to deter the institutionalization of the care receiver, the State realizes enormous savings.**

While it may not be appropriate in some very difficult cases for family to continue providing care at home, CRC services help many families who are deciding what is best for their family member and themselves. For these families, information and support services help deter the institutionalization of a loved one. It must be noted however, that among the 4,241 families on CRC respite waiting lists, some care receivers will be placed in a nursing home before CRC respite services became available. Unfortunately it is unknown how many of these families might have avoided or postponed that painful decision had subsidized respite care been an option.

4. Recommendations for ensuring that unmet needs of cognitively impaired persons and their families are identified and addressed with appropriate programs and

¹⁴ Based on \$41,292.45 annualized 2001 SNF Medi-Cal rate x 1,841 persons.

services.

In order to better understand the magnitude of needs experienced by adults with cognitive impairment and their families, it is important to first estimate the scope of the problem. An estimated 1.4 million people aged 18 years and older are diagnosed annually with adult onset cognitive disease/disorders (Appendix C, Table 1). Between 12.0 and 18.2 million individuals age 18 and over are currently living with the disease/disorder (Appendix C, Table 2). Even more striking, as many as 11 to 19 percent of the United States and California households may be dealing with the burden of caring for a loved one with an adult onset cognitive disease/disorder (Appendix C, Table 3).

The Three Top Needs Identified at Intake (Tables 12 and 13)

- 1) **Nearly seven out of ten (69%) family caregivers and 36% of service providers/general public requested basic information** about adult-onset cognitive disorders, a full range of caregiving issues, and the scope of CRC services. Resource information is critical at the time of diagnosis and remains important throughout the duration of the caregiving commitment. Information is needed and requested in the areas of home care and behavior management, emotional support, financial/legal considerations, placement help, and long-term care planning and alternatives.
- 2) **More than half (65%) of the caregivers and 15% of service providers¹⁵ indicated a need for respite care services.**
- 3) **Emotional support was a key need for well over half (65%) of families and 12% of service providers.** This indicates a **high demand for services, such as counseling and support groups**, where caregivers can begin to unburden themselves from the enormous stresses of their situations.

Additionally, direct care for the care receiver, legal information, behavior management advice, legal or financial assistance, and placement help were expressed needs for a significant proportion of families and professionals.

¹⁵ Respite needs identified by service providers indicate respite for the family caregiver.

Other Identified Needs

Table 11 depicts the top ten unmet needs/service gaps identified by CRCs throughout FY 2001-02 in their respective regions. The most common needs included: residential care options, support groups (bilingual and available to working caregivers), adult day care, services for traumatic brain injury survivors, case management, respite care, transportation, and a range of services in languages other than English.

Addressing Identified Service Needs

For CRCs across the state, education and training events continue to be one of the best vehicles for families and professionals to address the high demand for information about cognitive impairments and caregiver support options. For caregivers, the **education events** (Table 10) provide valuable information about care techniques and other low-cost interventions, as well as, opportunities to develop greater coping skills. For professionals, educational forums increase public awareness of cognitive impairments and interactions between the professional community and local resources. Additionally, the development of new training materials by the CRC system, such as program development in rural communities, and education for special populations, allows CRCs to address the tremendous demand for information, support and assistance for a wide range of caregiving experiences.

The 11 CRCs provided family-focused educational seminars and workshops for 12,922 CRC family clients and professionals. A significant 37,045 participants attended conferences and other educational events held regionally and statewide on issues related to caregiving and adult-onset cognitive impairments during FY 2001-02.

Throughout this annual report, we address steps to continue to develop, strengthen and provide CRC caregiver support services. Programs that offer information and emotional support, improve coping and day-to-day behavior management skills, provide access to legal/financial help, and offer respite care, can positively impact caregiver well being and strengthen social supports.

Strategic Plan Goals and Achievements

The three-year statewide strategic plan (2001-2003) developed jointly by the CRC Directors DMH, and SRC, to provide a vision for the CRC system in the new millennium was amended for 2001-2002. Below are the identified system goals for the year and accompanying accomplishments.

Goal A. Advocate for using National Family Caregiver Support Program (NFCSP) resources to the maximum benefit for California caregivers.

Background Information: The National Family Caregiver Support Program (NFCSP) was established with the enactment of the Older Americans Act Amendments of 2000. The program establishes services for family caregivers in the following areas:

information about available services, assistance in gaining access to supportive services, individual counseling, organization of support groups, and caregiving training to assist the caregivers in making decisions and solving problems relating to their caregiving roles; respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities, and supplemental services to complement the care provided by the caregivers. The NFCSP is administered in California through the 33 Areas Agencies on Aging (AAAs) of the California Department of Aging.

Objective 1. *Assume leadership role at state and local level to educate families, professionals, and the community about the needs of family caregivers and available resources.*

- All CRCs worked collaboratively with their local AAAs and other community-based organizations to expand services to caregivers using NFCSP funds.
- Throughout the state, CRC staff members were active in addressing the needs of family caregivers at public forums and Advisory Council Meetings for the AAAs in their respective service areas.
- The Director of the Los Angeles CRC served as co-chair on the AAA Department of Community and Senior Services strategic planning board subcommittee on caregiving and resources.

Objective 2. *Advocate at the state and local level to prevent the fragmentation of services to family caregivers.*

- To address fragmentation, CRC staff assumed a primary role in advocating for a seamless system of caregiver services at community forums and statewide coalition meetings.

Goal B: Advance the use of technology for the benefit of the CRC System and the caregivers it serves.

Objective 1. *Use Internet technology to disseminate program information and develop more interactive communication across the CRC system.*

- The CRC System, under the direction of Family Caregiver Alliance, expanded Link2Care, an Internet-based Information and Support system for Family Caregivers. During this past year, over 300 participants were enrolled in the Link2Care program. The goal of Link2Care is to increase caregiver well-being and coping skills through convenient access to information and connections to other caregivers. Resources on the program's website are designed for those providing care for someone who is living with a disease-related dementia such as Alzheimer's, stroke, Parkinson's and Multiple Sclerosis.
- A number of the eleven CRCs advanced services to caregivers using Internet

Technology. For example, several distributed monthly e-newsletters to cover caregivers and professionals; one developed an online support group for Lesbian/Gay/Bisexual/Transgender clients; and another implemented an advocacy tree with Caregiver Advocates using email and the Internet to disseminate information on caregiver advocacy action issues.

- Several CRCs expanded their websites to include more information about community resources, information on issues of concern to caregivers, and tips for coping. (See Appendix A for the addresses of these websites.)

Objective 2. Develop Internet-based client records system with direct entry and retrieval capability statewide.

- Throughout the last year, the CRCs have been actively involved in the development of a new integrated client record tracking system, using a Internet-based information network. The project will be tested in the fall of 2002 and fully implemented at all eleven CRC sites by June 2003.

Objective 3. Enable staff statewide to utilize the technology (marketing, research, web-based services, etc.)

- CRCs continued to expand their abilities to use technology in their work with caregivers. Around the state, a number of sites purchased laptops, established Internet access at satellite offices, or made software upgrades to increase efficiencies.

Objective 4. Develop strategic partnerships to enhance our use of technology in service delivery. Examples include the following:

- *Mountain CRC* collaborated with Golden Umbrella to develop new websites for the National Family Caregiver Support Program and the CRC.
- *Southern CRC* worked in collaboration with a UCLA-led project, ACCESS, which requires use of case management software and communication via the Internet with other project partners.
- In collaboration with the Adult and Aging Division of the Mendocino county Department of Social Services, *Redwood CRC* began the development of an electronic Information & Assistance system to be available countywide.
- In collaboration with several other key service providers, *Los Angeles CRC* developed and implemented a community calendar of events that listed trainings, education, and support groups. Los Angeles CRC also partnered with member organizations in the Antelope Valley Partners for Health to develop a computerized case-management program.

Goal C. Develop a strategy for managing the growth of the CRC system.

Objective 1. *Explore options for managing growth that are both cost-effective and efficient (e.g. establish buying-cooperative for technology products and services.)*

- CRC directors explored purchasing employee benefits (e.g. health insurance) as a statewide system in order to obtain better coverage at lower rates. Several CRCs worked with their host agencies to negotiate the cost-effective purchasing of products and services. CRC staff also established pilot cooperative agreements with other community agencies to share information and strategies as well as outreach costs.

Objective 2. *Strengthen existing management and administrative infrastructure to support continued growth of the CRC system.*

- Several CRCs added positions to enhance education and training services under both Chapter 1658 and NFCSP funds and perform record keeping and data entry. Staff also received training on data collection and reporting, computer skills to expedite recording procedures, personnel issues.

RECOMMENDATIONS

Based on the findings reported by the CRCs and analyzed by the SRC, the DMH agrees that the following recommendations for identifying and addressing the needs of caregivers should be given consideration.

1. Increase the number of caregivers receiving core CRC services through community-based collaborations and widely disseminated information and education campaigns targeting underserved caregivers, particularly minority and rural caregivers.
2. Promote public policy that advances the consumer-directed model of care for all caregivers and care receivers and supports the prevention, diagnosis, treatment, and cure of brain impairing conditions.
3. Improve assistance to working and isolated caregivers via technology, e.g., increase the number of caregivers using the Link2Care.
4. Explore establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.
5. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term care options for care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
6. Identify viable program options for Traumatic Brain Injury caregivers and their loved ones.
7. Carry out CRC research to: 1) measure and analyze the impact of cognitive disorders on family and caregiver well being, and (2) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Enhance local partnerships with AAAs to expand family consultations, counseling, and respite services to caregivers using National Family Caregiver Support Program funds.

TABLE 1
CAREGIVER RESOURCE CENTERS
TOTAL CLIENTS SERVED AND
AVERAGE AMOUNT OF SERVICE PER CLIENT (IN HOURS)

07/01/2001 through 06/30/2002

	Total	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total # of family clients ^a receiving at least one CRC service	14,475	2,369	1,168	1,692	1,510	1,965	1,385	700	549	1,544	681	912
Total # of family clients ^b receiving CRC core services	11,903	1,502	879	1,635	937	1,931	1,285	590	531	1,447	550	616
Avg. # of hours across ^c CRC core services (excluding respite)	5.1	4.8	5.2	2.3	5.3	3.2	3.7	7.7	14.2	8.2	4.9	4.6
Avg. # of hours across ^d CRC core services (including respite)	28.9	30.1	39.2	15.4	32.4	17.4	22.1	47.5	39.3	31.5	44.2	45.4

a Unduplicated count of client using services. Excludes wait lists.

b Core services include family consultation, follow up I&R, counseling, legal consultation, respite assistance, psychoeducational groups, and support groups. Excludes intake, assessment/reassessment and wait lists.

c N = 10,062. Based on the number of clients receiving "core" services (N = 11,903) minus respite users (N = 1,841).

d N = 11,903. Based on the number of clients receiving "core" services, as noted above in "b."

TABLE 2
CAREGIVER RESOURCE CENTERS
SERVICES SUMMARY: TOTAL CLIENTS SERVED^a
07/01/2001 through 06/30/2002

Clients Receiving Program Services by Type of Service ^b	Total Clients Served	Average # of Clients Served ^c	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Intake ^d	6,526	593	1,325	592	793	704	756	588	266	252	646	338	266
Follow-up I&R	4,857	442	486	102	1,521	442	1,229	190	260	155	254	123	95
Assessment	3,865	351	564	365	579	348	418	412	127	249	485	172	146
Reassessment													
Full Reassessment	3,990	363	506	361	416	391	472	418	239	242	602	57	286
Status Change	3,649	332	444	252	299	400	372	542	160	183	505	148	344
Family Consultation	10,243	931	1,315	800	1,436	723	1,615	1,129	380	520	1,334	474	517
(Avg. number per month)	2,156	196	196	191	208	158	275	225	138	149	418	131	67
Counseling (Individual)	301	27	47	21	18	15	46	17	30	17	18	39	33
(Avg. number per month)	56	5	8	3	5	3	9	3	9	3	2	4	7
Legal/Financial Consult.	398	40	57	31	17	7	72	80	48	16	37	33	0
Psychoeducational Groups	268	27	54	12	7	23	8	0	28	55	40	19	22

a Includes clients served during report period (unduplicated count per type of service).

b Not all CRCs provide all services. Service provision is only reported for clients funded through Chapter 1658 state funds (excludes clients served under special grant programs).

c The statewide average is computed as follows: the number of family clients receiving the service divided by the number of CRC sites providing the service.

d Excludes provider/general community intakes; also does not include written or phone inquiries where an intake was not conducted.

TABLE 2
CAREGIVER RESOURCE CENTERS
SERVICES SUMMARY: TOTAL CLIENTS SERVED
(CONT'D)
07/01/2001 through 06/30/2002

Clients Receiving Program Services by Type of Service	Total Clients Served	Average # of Clients Served ^a	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Respite Care	1,841	167	161	114	268	135	260	160	123	115	298	116	91
Respite: Adult Day Care	288	26	13	32	23	15	60	19	20	22	32	38	14
Respite: In-home	1,487	135	88	80	246	109	211	142	99	105	252	83	72
Respite: 24-hour (out of home)	34	--	8	1	1	16	0	1	1	0	2	2	2
Respite: 24-hour (in-home)	57	--	23	4	0	1	3	0	5	1	9	3	8
Respite: Camp	39	--	35	1	0	3	0	0	0	0	0	0	0
Respite: Transport	7	--	0	0	0	0	0	0	0	0	4	2	1
Respite: Other ^b	53	--	0	0	0	0	0	0	0	0	49	1	3
Respite (Avg. number per month)	859	78	71	66	149	42	121	67	50	58	112	67	56
Respite Wait List	4,241	386	678	333	748	152	438	353	232	221	659	116	311
Caregiver Retreat	271	39	38	4	0	52	0	0	35	52	79	0	11
Support Groups	921	84	30	155	27	67	36	154	117	92	129	57	57
(Avg. number per month)	253	23	8	43	7	17	8	41	41	26	32	17	13

^a The statewide average is computed as follows: the number of family clients receiving the service divided by the number of CRC sites providing the service.

^b Includes group respite, provided on an hourly basis.

TABLE 3
CAREGIVER RESOURCE CENTERS
DIRECT SERVICE UTILIZATION
07/01/2001 through 06/30/2002

Type of Service	Total Units of Service Provided ^a	Average Units Utilized	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Intake ^b	6,526 clients served	593	1,325	592	793	704	756	588	266	252	646	338	266
Follow-up I&R ^c	7,868 hours	715	247	55	1,272	204	5,237	191	285	78	173	75	51
Assessment	3,868 assess. conducted	352	564	365	579	348	421	412	127	249	485	172	146
Reassessment													
Full Reassessment	5,059	460	628	431	491	472	540	518	295	356	916	65	347
Status Change	3,807 reassess. conducted	346	454	252	310	406	393	613	160	187	526	159	347
Family Consultation ^c	23,745 hours	2,159	2,380	2,454	1,675	1,399	2,599	2,923	1,140	1,924	5,006	1,237	1,008
Counseling (Individual) ^c	1,549 hours	141	276	110	83	89	117	53	322	70	68	190	171

a Average unites is based on the number of CRC sites providing service.

b Excludes provider/general community intakes and written or phone inquiries where an intake was not conducted.

c Unit of service is 15 minutes. Units have been converted to hours for statewide reporting.

TABLE 3
DIRECT SERVICE UTILIZATION (CONT'D)
07/01/2001 through 06/30/2002

Type of Service	Total Units of Service Provided	Average Units Utilized	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Legal/Financial Consultations	444 hours	44	77	31	31	7	65	80	66	16	37	34	0
Psychoeducational Groups ^a	4,520 hours	452	1,919	62	138	312	92	0	362	650	628	110	247
Total Respite ^b	283,115 hours	25,738	37,976	29,949	21,455	25,494	27,267	23,637	23,472	13,340	33,755	21,601	25,169
Respite: Adult Day Care ^c	11,164 hours	1,015	1,439	1,782	1,065	337	1,682	685	933	567	657	1,436	581
Respite: In-home	181,502 hours	16,500	23,337	15,124	13,544	19,213	15,373	18,818	15,309	9,323	23,907	10,953	16,601
Respite: 24-hour ^d (out of home)	293 24 hr days	--	30	2	19	156	0	1	15	0	19	8	43
Respite: 24-hour (in home)	504 24 hr days	--	157	95	0	2	5	0	53	2	38	16	136
Respite: Camp ^a	231 24 hr days	--	78	23	0	130	0	0	0	0	0	0	0
Respite: Transportation	663 1-way trip	--	0	0	0	0	0	0	0	0	137	190	336
Respite: Other	4,106 hours	--	0	0	0	0	0	0	0	0	3,881	20	205
Avg. # Months on Respite Wait List	N/A	20	21	16	11	48	47	10	22	7	12	8	17
Caregiver Retreat ^a	947 24 hr days	135	89	4	0	104	0	0	43	169	351	0	187
Support Groups ^a	7,524 hours	684	144	1,514	310	374	167	1,380	1,124	700	788	666	357

a Total hours reflect the sum of hours received by each participant at a group event

b All respite figures have been converted to hours to obtain total respite hours.

c Assumes an average of seven hours per day.

d Includes overnight and weekend respite care at hospitals and residential facilities.

TABLE 4
CAREGIVER RESOURCE CENTERS
AMOUNT OF CRC SERVICE PER CLIENT (in hours)

07/01/2001 through 06/30/2002

CRC Service Type	Average Hours ^a	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Follow-Up I&R	0.8	0.5	0.5	0.8	0.5	1.1	1.0	1.1	0.5	0.7	0.6	0.5
Family Consultation	2.3	1.8	3.1	1.2	1.9	1.6	2.6	3.0	3.7	3.8	2.6	1.9
Counseling (Individual)	4.5	3.6	5.2	4.6	3.4	2.5	3.1	10.7	4.1	3.8	4.9	5.2
Legal/Financial Consult	1.1	1.4	1.0	1.8	1.0	0.9	1.0	1.4	1.0	1.0	1.0	0.0
Psychoeducational Groups	16.9	35.5	5.2	19.7	13.6	11.5	0.0	12.9	11.8	15.7	5.8	11.2
Respite Care	329.6 ^b	534.9	453.8	144.0	607.0	225.3	352.8	469.4	230.0	301.4	322.4	449.4
Support Groups	8.2	4.8	9.8	11.5	5.6	4.6	9.0	9.6	7.6	6.1	11.7	6.3

a Based on the total number of units (hours) utilized per service divided by the total number of family clients receiving the service during the report period.

b For respite care, the calculation is based on the total number of respite hours divided by the respite average monthly caseload. The total amount of respite care per family client breaks down into 27 hours per month or 6 hours per week.

TABLE 5
CAREGIVER RESOURCE CENTERS
CASE STATUS SUMMARY
07/01/2001 through 06/30/2002

Client Case Status	Total	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total Active Cases at Start of Report Period	5,617	665	497	808	434	600	649	306	289	601	299	469
# New Clients Added	3,926	571	365	592	349	435	421	127	249	488	177	152
# Client Reactivated ^a	223	17	5	1	0	24	73	10	3	55	7	28
Total Active Cases During Report Period ^b	9,766	1,253	867	1,401	783	1,059	1,143	443	541	1,144	483	649
# Cases Made Inactive	449	160	0	33	3	122	38	0	0	0	6	87
# Active Cases Closed	2,407	237	241	230	149	228	383	146	176	288	107	222
# Inactive Cases Closed	417	18	40	71	80	101	22	21	1	31	22	102
Reason closed												
--Caregiver died	40	3	9	6	0	8	2	1	1	5	1	4
--Caregiver moved	132	11	18	20	0	11	5	15	9	21	8	14
--Patient died	1,105	155	87	142	0	117	129	71	75	178	51	100
--Other ^c	1,110	129	68	92	30	129	222	84	134	145	57	2
# Patients placed in facilities ^c	495	65	4	63	0	44	38	80	56	132	4	9
--SNF	326	33	4	39	0	27	23	50	46	97	2	5
--Rehab	2	0	0	0	0	0	1	0	0	1	0	0
--Acute Hospital	3	1	0	1	0	0	0	0	0	1	0	0
--Board & Care	123	17	0	11	0	8	13	29	9	31	2	3
--Other	41	14	0	12	0	9	1	1	1	2	0	1
Total Active Cases at End of Report Period ^d	6,910	856	626	1,138	631	709	722	297	365	856	370	340

a Cases previously closed or inactive made active by providing new CRC services.

b Includes clients who have been assessed and are on the CRC respite wait list only or clients not currently using CRC services.

c Includes caregivers who become ineligible or decline further services, or who cannot be reached for reassessment.

d Subtracts cases made inactive and active cases closed from the Total Active Cases during the fiscal year.

TABLE 5b
CAREGIVER RESOURCE CENTERS^{abc}
CAREGIVER ASSESSMENT RETURN RATES/CES-D SCORE
07/01/2001 through 06/30/2002

	July – September 2001				October – December 2001				January – March 2002				April – June 2002				TOTAL			
CRC	Total Assessed	Questionnaires Returned		Avg. CE S-D Score	Total Assessed	Questionnaires Returned		Avg. CE S-D Score	Total Assessed	Questionnaires Returned		Avg. CES-D Score	Total Assessed	Questionnaires Returned		Avg. CES-D Score	Total Assessed	Questionnaires Returned		Avg. CES-D Score
	#	#	%		#	#	%		#	#	%	Score	#	#	%	Score	#	#	%	Score
Bay Area/FCA	131	107	81%	19	112	83	74%	22	144	96	66%	25	177	123	69%	21	564	409	72%	22
Redwood	85	76	89%	16	91	71	78%	18	95	71	74%	16	94	62	65%	20	365	280	76%	17
Los Angeles	171	161	94%	19	146	136	93%	20	116	105	90%	19	146	127	86%	20	579	529	91%	19
Inland	73	61	83%	22	65	47	72%	22	74	51	68%	23	136	100	73%	20	348	259	74%	22
Del Oro	87	51	58%	19	71	43	60%	17	128	77	60%	17	132	76	57%	20	418	247	59%	18
Southern	109	89	81%	17	83	73	87%	19	89	79	88%	17	131	110	83%	16	412	351	85%	17
Coast	43	43	100%	20	24	23	95%	18	33	32	96%	19	27	27	100%	18	127	125	98%	19
Mountain	44	36	81%	19	29	19	65%	17	77	54	70%	20	99	63	63%	18	249	172	69%	18
Valley	70	70	100%	21	87	85	97%	20	151	151	100%	19	177	175	98%	20	485	481	99%	20
Del Mar	42	39	92%	17	40	38	95%	21	44	41	93%	17	46	39	84%	16	172	157	91%	18
Orange	33	31	93%	19	29	26	89%	26	40	38	95%	19	44	40	90%	16	146	135	92%	20
Total	888	764	86%	19	777	644	82%	20	991	795	80%	19	1,209	942	77%	19	3,865	3,145	81%	19

a Includes questionnaires returned by the end of the reporting period.

b A revised assessment tool was implemented in January 1998; the mail-back questionnaire was limited only to items related to the CES-D (depression) score.

c A score of 16 or higher on the CES-D indicates the presence of symptoms of clinical depression.

TABLE 6
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR VOUCHER SERVICES
07/01/2001 through 06/30/2002

Expenditures ^a	Total \$	Bay Area CRC/FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
In Home Respite ^b (Avg. # per family client)	\$2,417,468 \$1,626	\$230,392 \$2,618	\$163,614 \$2,045	\$590,000 \$2,398	\$163,472 \$1,500	\$222,918 \$1,056	\$205,641 \$1,448	\$171,350 \$1,731	\$136,276 \$1,298	\$242,061 \$961	\$134,873 \$1,625	\$156,871 \$2,179
Adult Day Care Respite ^b (Avg. # per family client)	\$388,891 \$1,350	\$34,076 \$2,621	\$63,461 \$1,983	\$44,952 \$1,954	\$10,689 \$713	\$62,718 \$1,045	\$21,461 \$1,130	\$36,620 \$1,831	\$19,796 \$900	\$16,637 \$520	\$52,341 \$1,377	\$26,140 \$1,867
24-hour In-Home Respite ^b (Avg. # per family client)	\$38,815 \$681	\$9,697 \$422	\$4,380 \$1,095	\$0 \$0	\$200 \$200	\$820 \$273	\$0 \$0	\$5,785 \$1,157	\$428 \$428	\$4,039 \$449	\$1,866 \$622	\$11,600 \$1,450
24-hour Out-of-Home Respite ^b (Avg. # per family client)	\$22,421 \$659	\$4,270 \$534	\$250 \$250	\$1,776 \$1,776	\$11,230 \$702	\$0 \$0	\$700 \$700	\$1,500 \$1,500	\$0 \$0	\$675 \$338	\$960 \$480	\$1,060 \$530
Respite Camp (Avg. # per family client)	\$20,481 \$525	\$19,125 \$546	\$300 \$300	\$0 \$0	\$1,056 \$352	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0
Other Respite ^b (Avg. # per family client)	\$17,792 \$336	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$0 \$0	\$15,412 \$315	\$330 \$330	\$2,050 \$683
Legal Consultation (Avg. # per family client)	\$42,565 \$107	\$7,730 \$136	\$2,170 \$70	\$3,515 \$207	\$700 \$100	\$4,912 \$68	\$9,200 \$115	\$6,550 \$136	\$1,700 \$106	\$2,738 \$74	\$3,350 \$102	\$0 \$0
Counseling (Individual) ^c (Avg. # per family client)	\$46,104 \$259	\$8,925 \$288	\$5,500 \$262	\$0 \$0	\$724 \$52	\$3,300 \$138	\$0 \$0	\$8,670 \$456	\$2,950 \$174	\$3,885 \$299	\$12,150 \$312	\$0 \$0
Total	\$2,994,537	\$314,215	\$239,675	\$640,243	\$188,071	\$294,668	\$237,002	\$230,475	\$161,150	\$285,447	\$205,870	\$197,721

a These figures include only funds expended under Chapter 1658 contracts; special grants are excluded. However, respite expenditures also include some funds collected from client co-payments, used to extend CRC respite budgets. Expenditures reflect voucher costs only; salaried CRC staff time is excluded.

b Average respite expenditures are based on the total number of family clients receiving each type of respite (includes short-term and one-time-only respite clients). See also Table 8.

c Reflects 301 clients receiving vouchered (subcontracted) counseling only. Individual sites vary as to whether counseling services are provided by CRC staff or by subcontract.

TABLE 7
CAREGIVER RESOURCE CENTERS
COMPARISON OF CRC RESPITE VOUCHER COSTS
AND SKILLED NURSING FACILITY (SNF) COSTS
07/01/2001 THROUGH 06/30/2002

Service	Average Cost per Client per Month	Average Cost per Client per Year
CRC Respite (Voucher)	\$300 ^a	\$3,383 ^b
Skilled Nursing Facility: Medi-Cal	\$3,393 ^c	\$41,292
Skilled Nursing Facility: Private Pay	\$4,322 ^d	\$51,864

a Based on total expenditures and family client caseload figures for CRC respite voucher services for FY 2001-2002 (See Table 9). Includes an average co-payment of \$18.

b Assumes an average of seven hours of respite care per week for 12 months (See Table 9).

c Source: California Department of Health Services, Medi-Cal Policy Division, Rate Development Branch, Long-Term Care Reimbursement Unit. (Note: Based on weighted average of \$113.13 per day, effective 8/1/2001.)

d Source: This 2002 estimate was taken reported by California Advocates for Nursing Home Reform (CANHR), http://www.canhr.org/medcal/EPRrates_2002.html.

TABLE 8
CAREGIVER RESOURCE CENTERS
HOURS OF RESPITE CARE PROVIDED
07/01/2001 through 06/30/2002

Respite	Total	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total Number of Family Clients Served	1,841	161	114	268	135	260	160	123	115	298	116	91
Average Monthly Respite Caseload ^a	859	71	66	149	42	121	67	50	58	112	67	56
Total Hours of Respite ^b	283,115	37,976	29,949	21,455	25,494	27,267	23,637	23,472	13,340	33,755	21,601	25,169
Average Number of Hours of Respite per Family Client	330	535	454	144	607	225	353	469	230	301	322	449
Average Number of Hours of Respite per Family Client per Month ^c	28	45	38	12	51	19	29	39	19	25	27	37
Average Number of Hours of Respite per Family Client per Week ^d	6	10	9	3	12	4	7	9	4	6	6	9

a Figure represents the total monthly caseload at all 11 CRCs statewide; the average monthly caseload across CRCs is 78 family clients receiving respite per month per CRC site.

b Out-of-home respite for day care was calculated at an average of 7 hours per day. Excludes respite transportation assistance.

c Average Number of Hours of Respite per Family Client were computed based on 12 months of service provision.

d Calculated using 4.3 weeks per month.

TABLE 9
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR RESPITE VOUCHER SERVICES
07/01/2001 through 06/30/2002

Respite	Total	Bay Area CRC/FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total Cost of Respite Services ^a	\$3,212,812	\$335,351	\$268,679	\$670,925	\$201,304	\$319,327	\$255,775	\$253,970	\$176,459	\$308,904	\$215,061	\$207,057
Total Reimbursement (co-payment) by Family Clients ^b	\$306,946	\$37,790	\$36,674	\$34,198	\$14,657	\$32,871	\$27,973	\$38,715	\$19,959	\$30,080	\$24,692	\$9,337
Total CRC Respite Expenditure ^c	\$2,905,866	\$297,561	\$232,005	\$636,727	\$186,647	\$286,456	\$227,802	\$215,255	\$156,500	\$278,824	\$190,369	\$197,720
Total No. of Family Clients	1,841	161	114	268	135	260	160	123	115	298	116	91
Total # of Family Clients Contributing Co-payment ^d	1,406	115	96	226	124	196	135	118	67	181	99	49
Average Respite Caseload per Month ^e	859	71	66	149	42	121	67	50	58	112	67	56
Percent of Families Contributing a Co-payment	76%	71%	84%	84%	92%	75%	84%	96%	58%	61%	85%	54%
Average Annual CRC Costs per Family Client ^f	\$3,383	\$4,191	\$3,515	\$4,273	\$4,444	\$2,367	\$3,400	\$4,305	\$2,698	\$2,490	\$2,841	\$3,531
Average Annual Reimbursement (co-payment) per Family Client	\$218	\$329	\$382	\$151	\$118	\$168	\$207	\$328	\$298	\$166	\$249	\$191
Average Annual Cost per Family client	\$3,601	\$4,520	\$3,897	\$4,424	\$4,562	\$2,535	\$3,607	\$4,633	\$2,996	\$2,656	\$3,090	\$3,722
Average CRC Cost per Family Client per Month	\$282	\$349	\$293	\$356	\$370	\$197	\$283	\$359	\$225	\$208	\$237	\$294
Average Reimbursement (co- payment) per Family Client per Month	\$18	\$27	\$32	\$13	\$10	\$14	\$17	\$27	\$25	\$14	\$21	\$16
Average Cost per Family Client per Month	\$300	\$376	\$325	\$369	\$380	\$211	\$300	\$386	\$250	\$222	\$258	\$310

a Excludes costs of staff time for arranging and monitoring respite services and for administrative costs.

b Includes share of cost for families using "direct pay" respite.

c Total CRC respite expenditure includes some funds generated from client co-payments which are used to augment CRC respite budgets.

d CRCs provide some emergency and short-term respite where families do not pay a co-payment.

e Calculated based on the total number of family clients served divided by the number of months in the report period.

f Calculated based on the average respite caseload per month.

TABLE 10
CAREGIVER RESOURCE CENTERS
EDUCATION AND TRAINING FACILITIES
07/01/2001 through 06/30/2002

Education/Training Activity Type	Total CRCs ^a	Bay Area CRC/ FCA	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
FAMILY-FOCUSED EDUCATION/TRAINING												
1. Total number of persons attending	12,922	1,105	487	1,089	217	4,423	2,652	365	498	1,005	333	748
OTHER EDUCATION/TRAINING EVENTS												
2. Total number of persons attending	7,314	855	568	581	160	1,282	1,735	293	1,045	1,407	90	375
ORIENTATION TO CRC SERVICES												
3. Total number of persons attending	16,029	582	425	246	159	5,271	5,383	55	238	2,970	518	182
Total	37,342	2,542	1,480	1,916	536	10,996	9,770	713	1,781	5,382	941	1,305

a Duplicated Count

TABLE 11
 CAREGIVER RESOURCE CENTERS
 TOP TEN UNMET NEEDS/SERVICE GAPS IDENTIFIED
 BY CRCS IN THEIR SERVICE REGIONS
 07/01/2001 through 06/30/2002

NEEDS IDENTIFIED	# OF CRCS REPORTING
Residential Care/Assisted Living (Affordable)	10
Support Groups (Bi-lingual, TBI, etc.)	10
Adult Day Care	8
TBI Programs	7
Case Management	7
Housing (Affordable)	5
Services in Languages Other Than English	5
Respite Care	4
Transportation	3
Education	3

TABLE 12
CAREGIVER RESOURCE CENTERS
MAJOR NEEDS/INFORMATION REQUESTED BY
FAMILIES/CAREGIVERS AT CRC INTAKE ^a
07/01/2001 through 06/30/2002

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	4,512	69%	1
Respite Care (for the caregiver) ^c	4,239	65%	2
Emotional Support	4,215	65%	3
Direct Care of the Adult With Brain Impairment ^d	2,820	43%	4
Financial Advice/Aid	1,664	25%	5
Behavior Management Advice	1,373	21%	6
Legal Information/Advice	1,320	20%	7
Other	922	14%	8
Placement Help	853	13%	9
Diagnostic/Medical Advice	467	7%	10
Rehabilitation	98	2%	11
Public Policy/Research	14	0%	12

a Needs identified are based on responses from 6,527 families/caregivers at intake.

b Percentages exceed 100% due to multiple problems/needs.

c Respite care refers to expressions of wanting "a break" from caregiving and questions about CRC respite programs or other community resources which provide respite care.

d Direct care of brain-impaired adults refers to questions about hiring home help, arranging care services for long-distance caregivers, equipment needs, medical supplies, home safety, basic care strategies (e.g. lifting), etc.

TABLE 13
CAREGIVER RESOURCE CENTERS
MAJOR NEEDS/INFORMATION REQUESTED BY
PROVIDERS/GENERAL PUBLIC AT CRC INTAKE ^a
07/01/2001 through 06/30/2002

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	637	36%	1
Respite Care (for the Caregiver) ^c	260	15%	2
Emotional Support	210	12%	3
Other	188	11%	4
Direct Care of the Adult With Brain Impairment ^d	172	10%	5
Placement Help	85	5%	6
Behavioral Management Advice	70	4%	7
Legal Information/Advice	56	3%	8
Financial Advice/Aid	33	2%	9
Diagnostic/Medical Advice	23	1%	10
Training	17	1%	11
Rehabilitation	9	1%	12
Public Policy/Research	6	0%	13

a Needs identified are based on responses from 1,766 providers/general public callers at intake.

b Percentages exceed 100% due to multiple problems/needs.

c Respite care refers to expressions of wanting "a break" from caregiving and questions about CRC respite programs or other community resources which provide respite care.

d Direct care of brain-impaired adults refers to questions about hiring home help, arranging care services for long-distance caregivers, equipment needs, medical supplies, home safety, basic care strategies (e.g. lifting), etc.

FIGURE 1
CAREGIVER RESOURCE CENTERS
TOP FOUR SERVICES AND NUMBER OF CLIENTS SERVED
FY 2001-2002

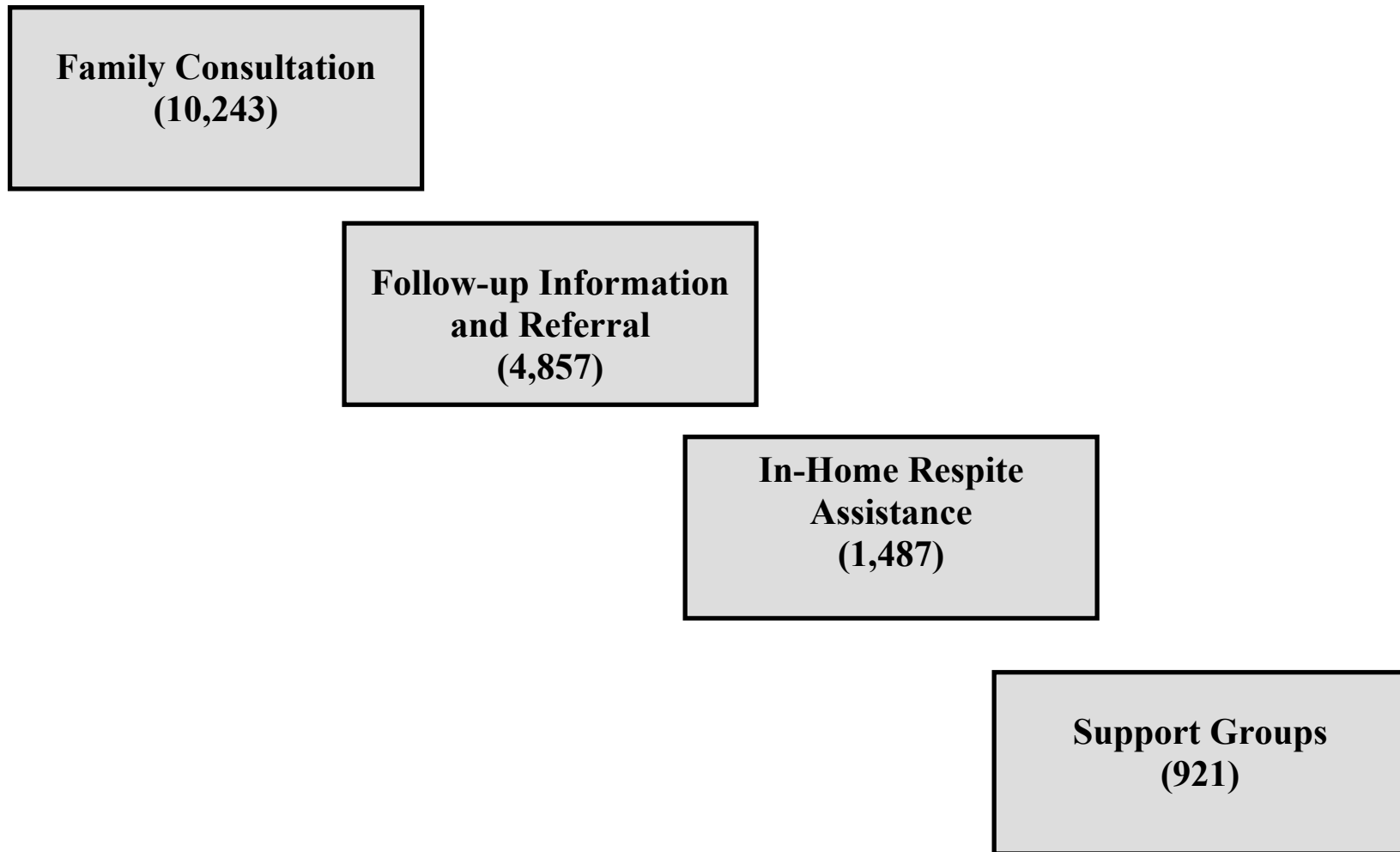
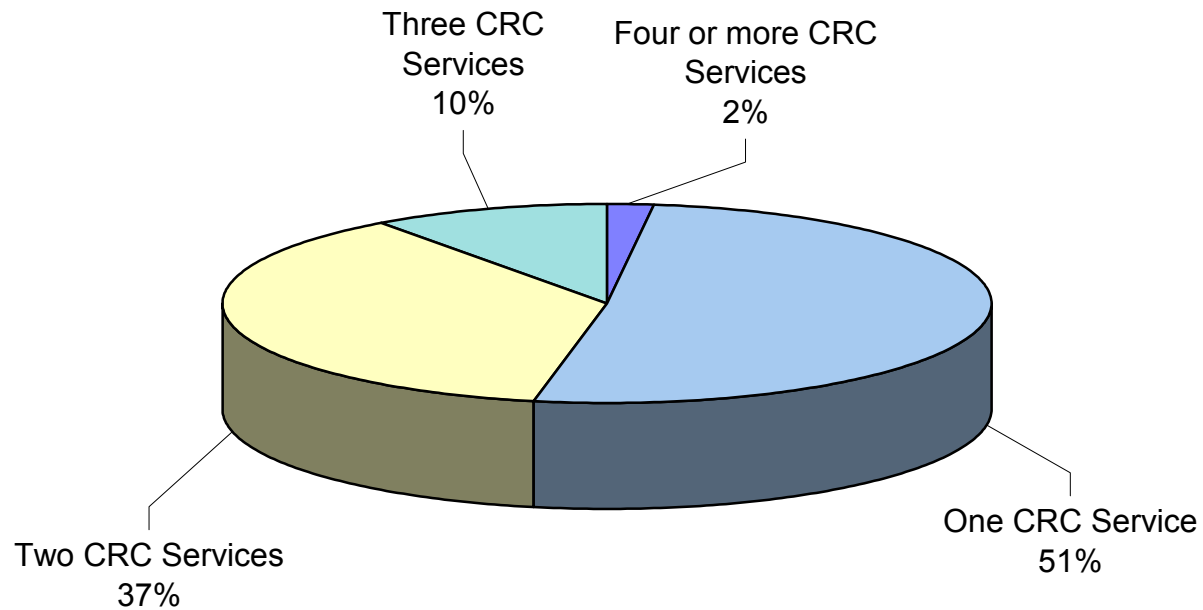


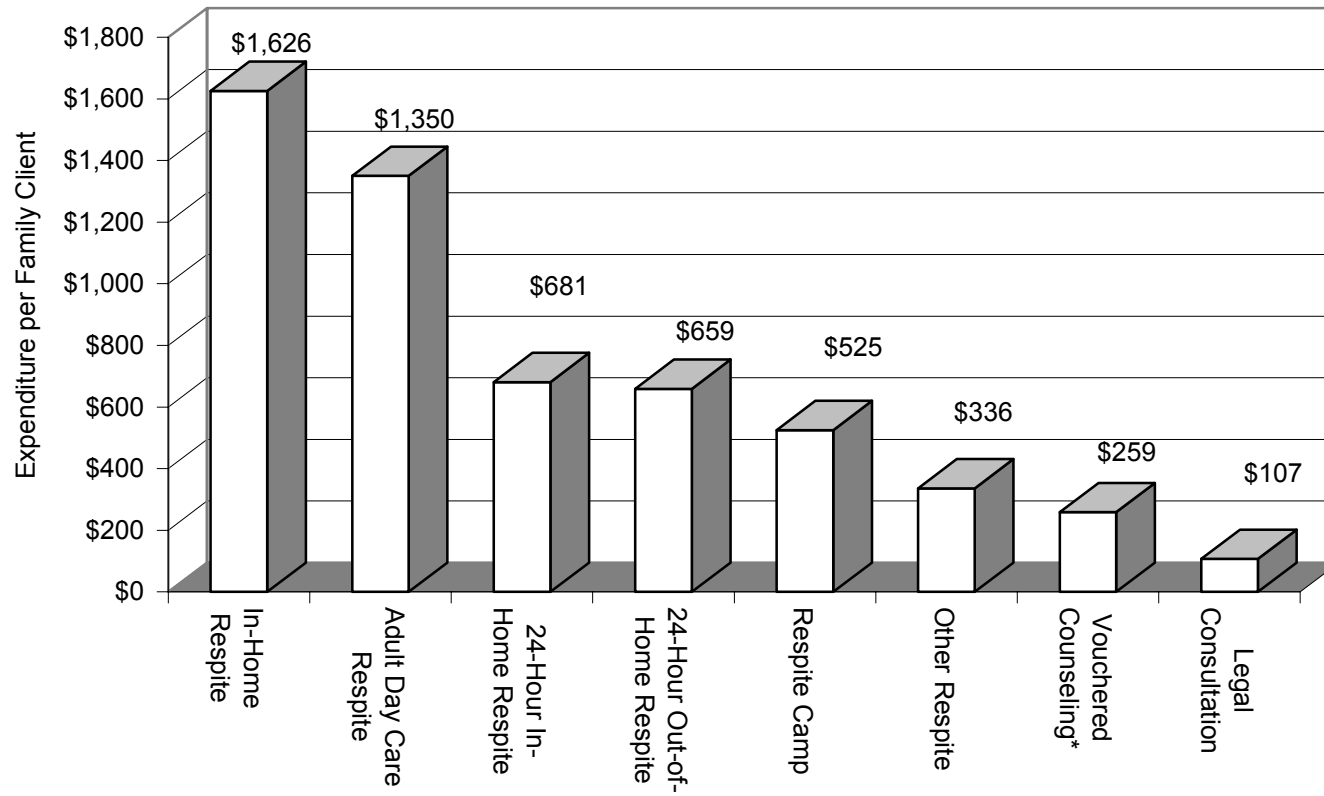
FIGURE 2
CAREGIVER RESOURCE CENTERS
THE PROPORTION OF FAMILY CAREGIVERS RECEIVING ONE,
TWO, THREE, OR FOUR PLUS SERVICES ^A
FY 2001-2002



N = 11,903

^a Includes CRC "core" services only
focused education, legal consultation, and respite). Access services are excluded (intake, assessment, and reassessment).

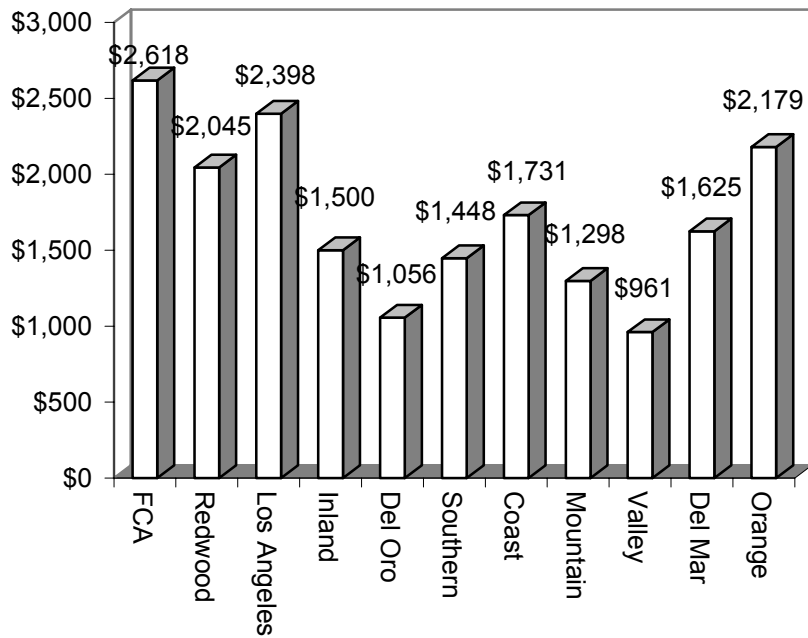
FIGURE 3
 CAREGIVER RESOURCE CENTERS
 AVERAGE COST PER YEAR PER FAMILY CLIENT FOR
 CRC VOUCHER SERVICES, FY 2001-2002



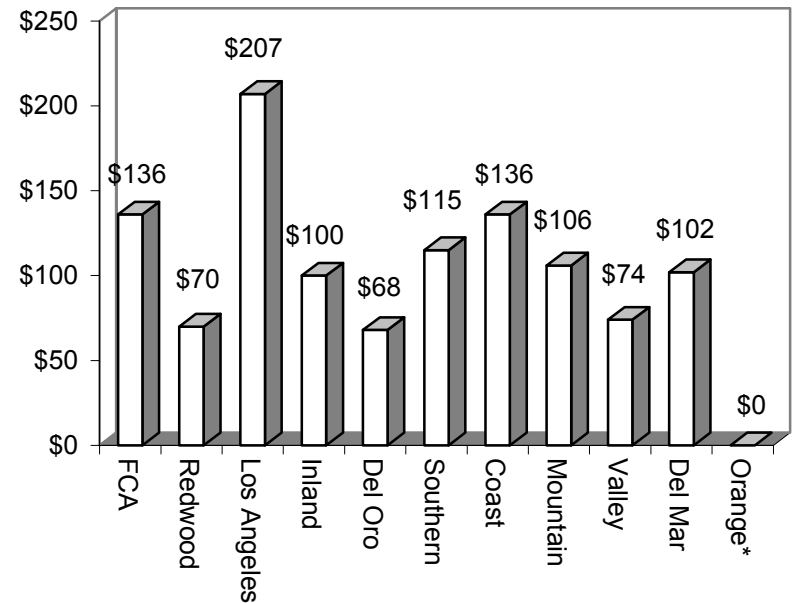
*Excludes counseling provided by salaried CRC staff.

FIGURE 4
CAREGIVER RESOURCE CENTERS
ANNUAL COST PER FAMILY CLIENT BY CRC SITE:
IN-HOME RESPITE AND LEGAL CONSULTATIONS
FY 2001-2002

In-Home Respite



Legal Consultations



* Orange CRC offers pro bono legal services and free group legal workshops as part of their family-focused education and training services.

FIGURE 5
 CAREGIVER RESOURCE CENTERS
 RESPITE CARE BY CRC SITE – TOTAL NUMBER OF FAMILY CLIENTS
 SERVED IN FY 2000-2001 AND FY 2001-2002

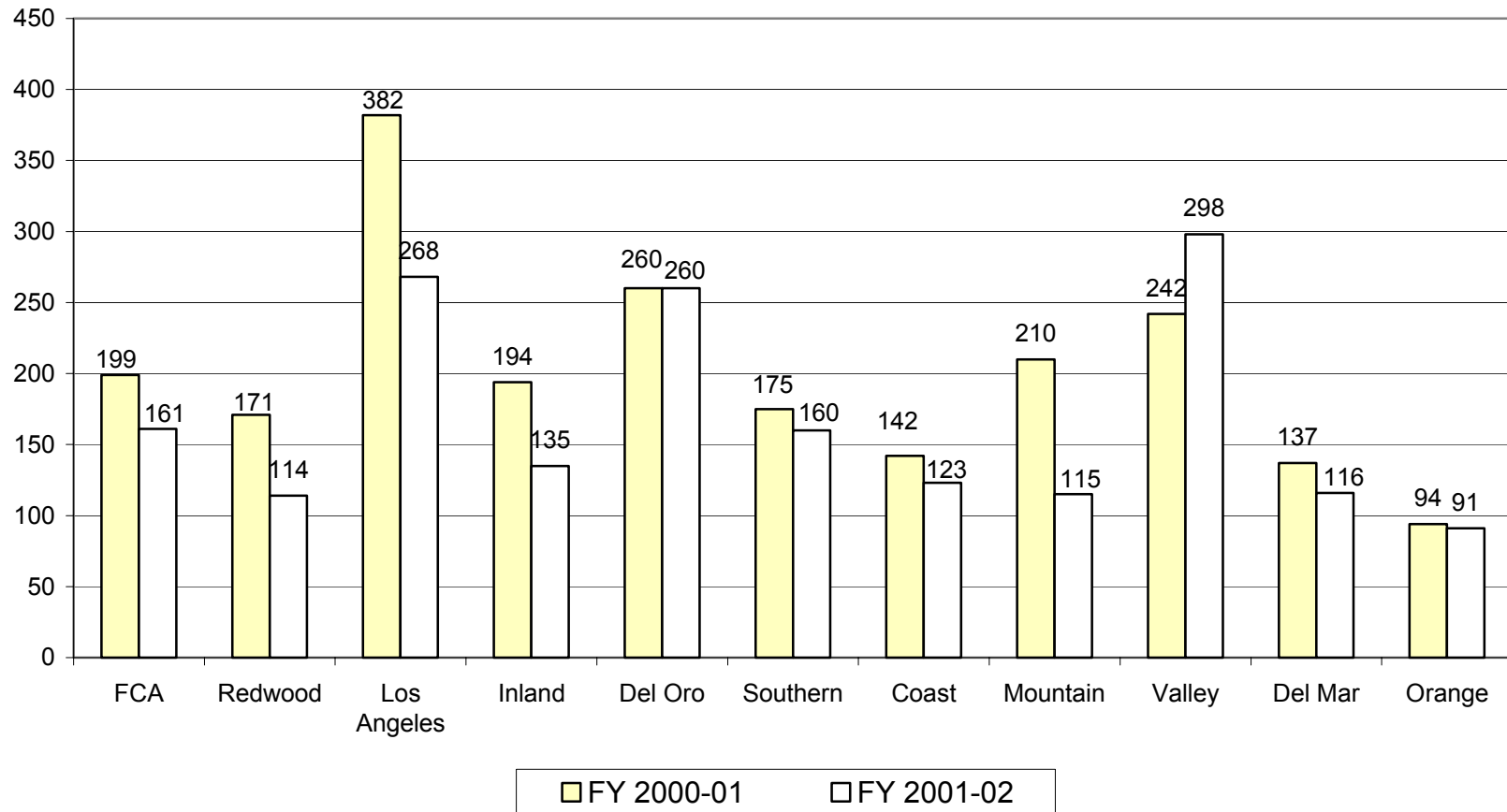


FIGURE 6
 CAREGIVER RESOURCE CENTERS
 CRC RESPITE USE BY TYPE OF RESPITE:
 PROPORTION OF CLIENTS SERVED AND PROPORTION OF HOURS UTILIZED
 FY 2001-2002

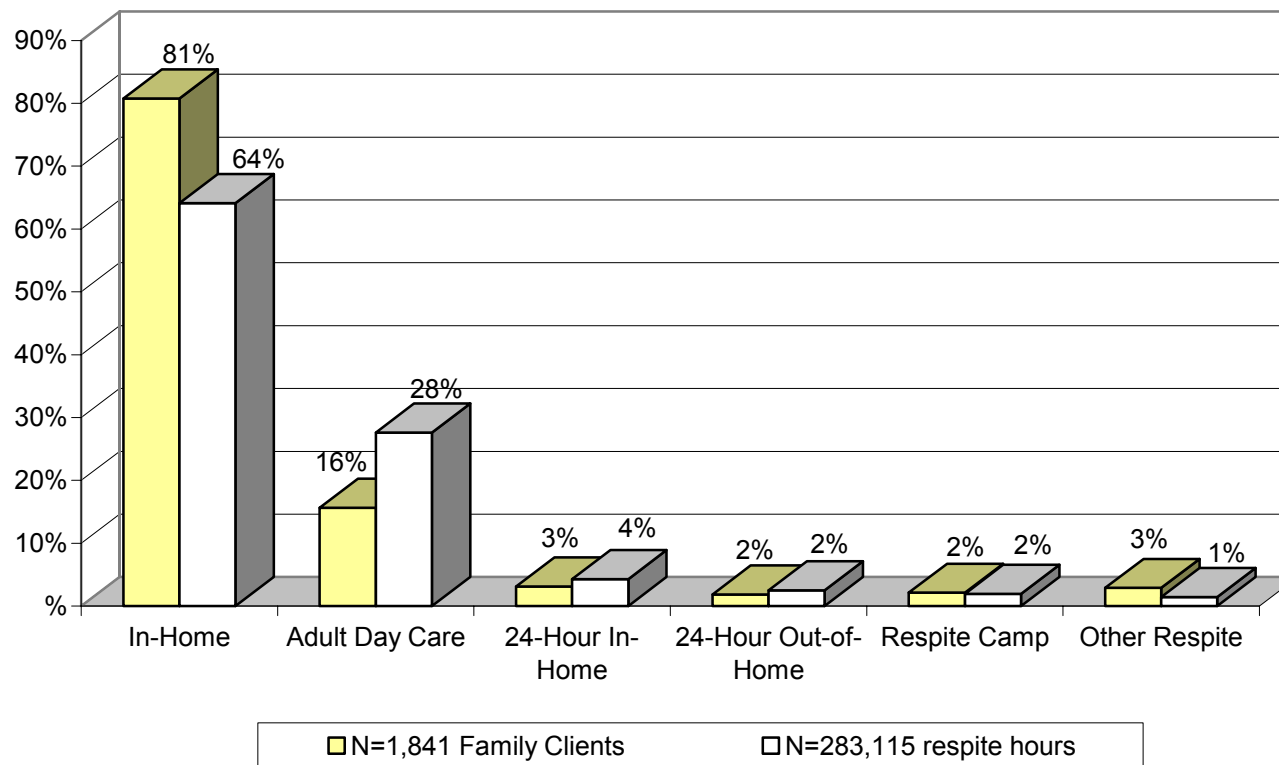
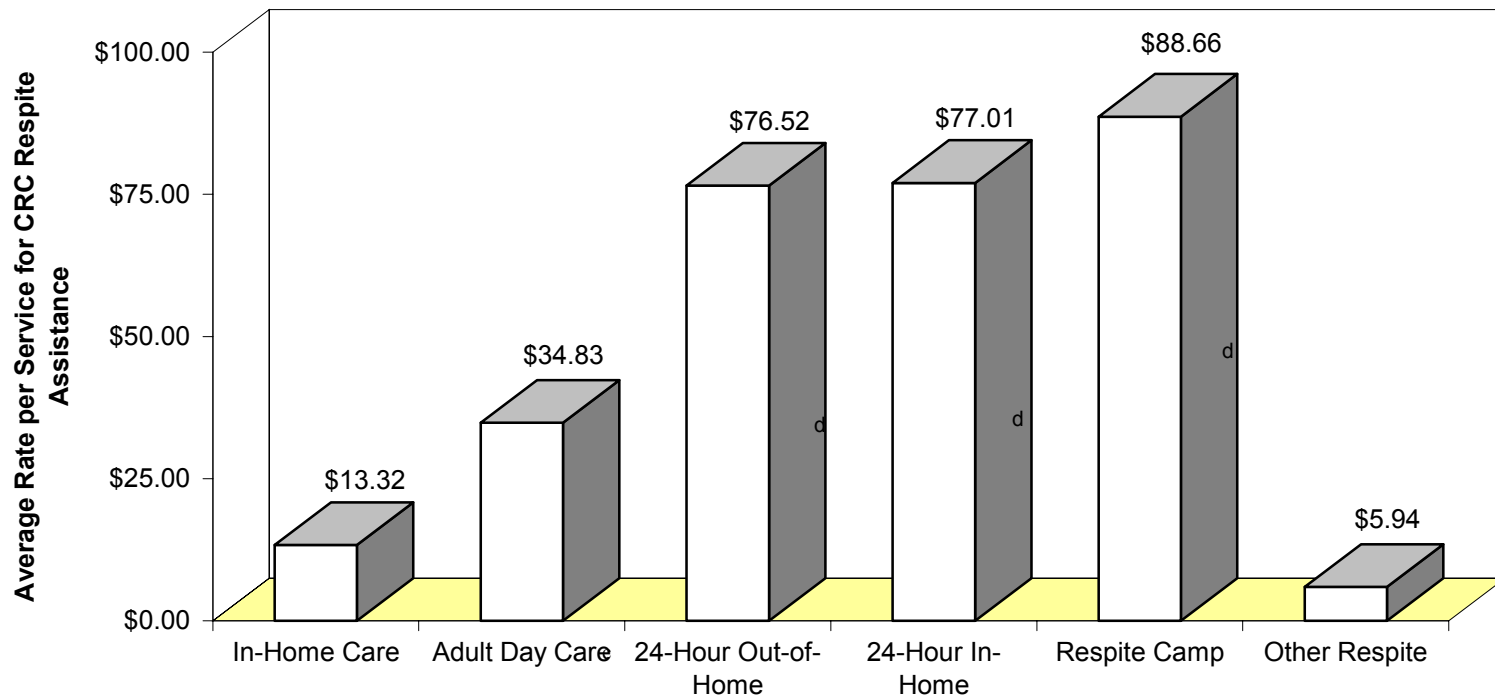


FIGURE 7
 CAREGIVER RESOURCE CENTERS
 RESPITE CARE: AVERAGE RATE PER SERVICE ^a
 FY 2001-2002



^a Excludes client co-payments.

^b Per hour.

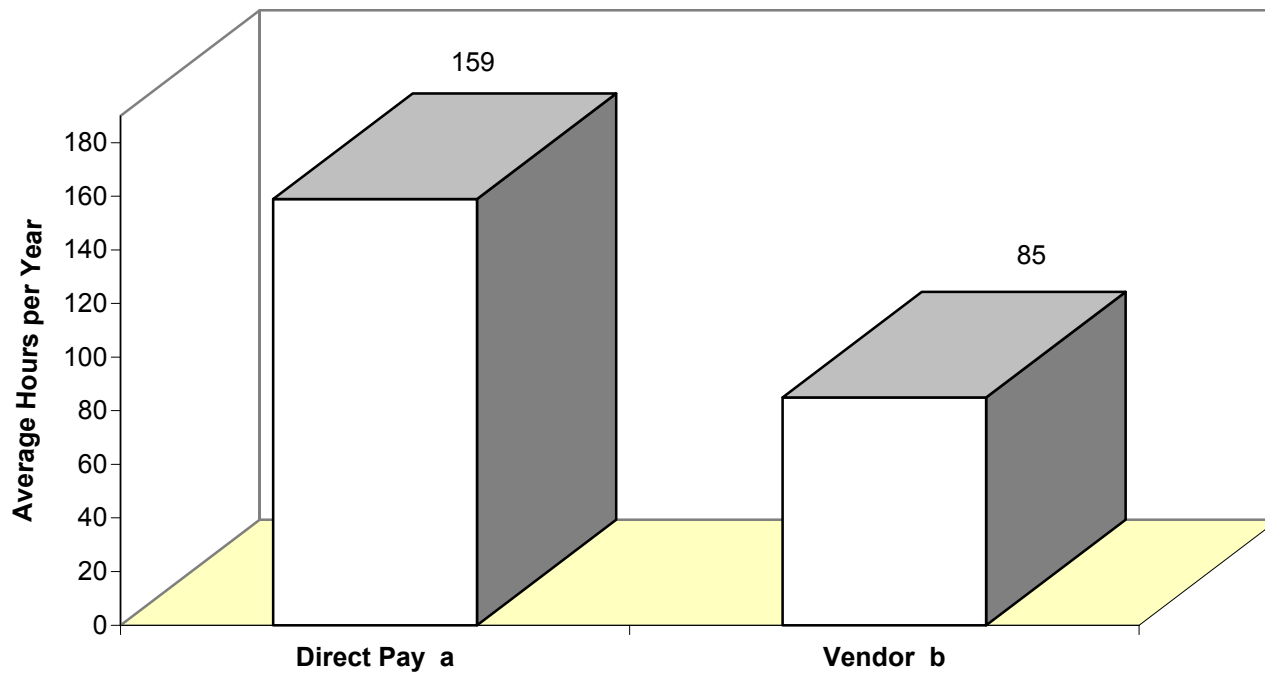
^c Per 7-hour day

^d Per 24-hour day

^e Group respite per four hour day (average of 4-9 participants per group).

Note: The average rate per service is calculated by using the total respite expenditures for a type of respite service and dividing by the total units of service provided for a type of respite service.

FIGURE 8
CAREGIVER RESOURCE CENTERS
IN-HOME RESPITE CARE – AVERAGE AMOUNT OF SERVICE IN HOURS PER CLIENT:
VENDOR AND DIRECT PAY
FY 2001-2002

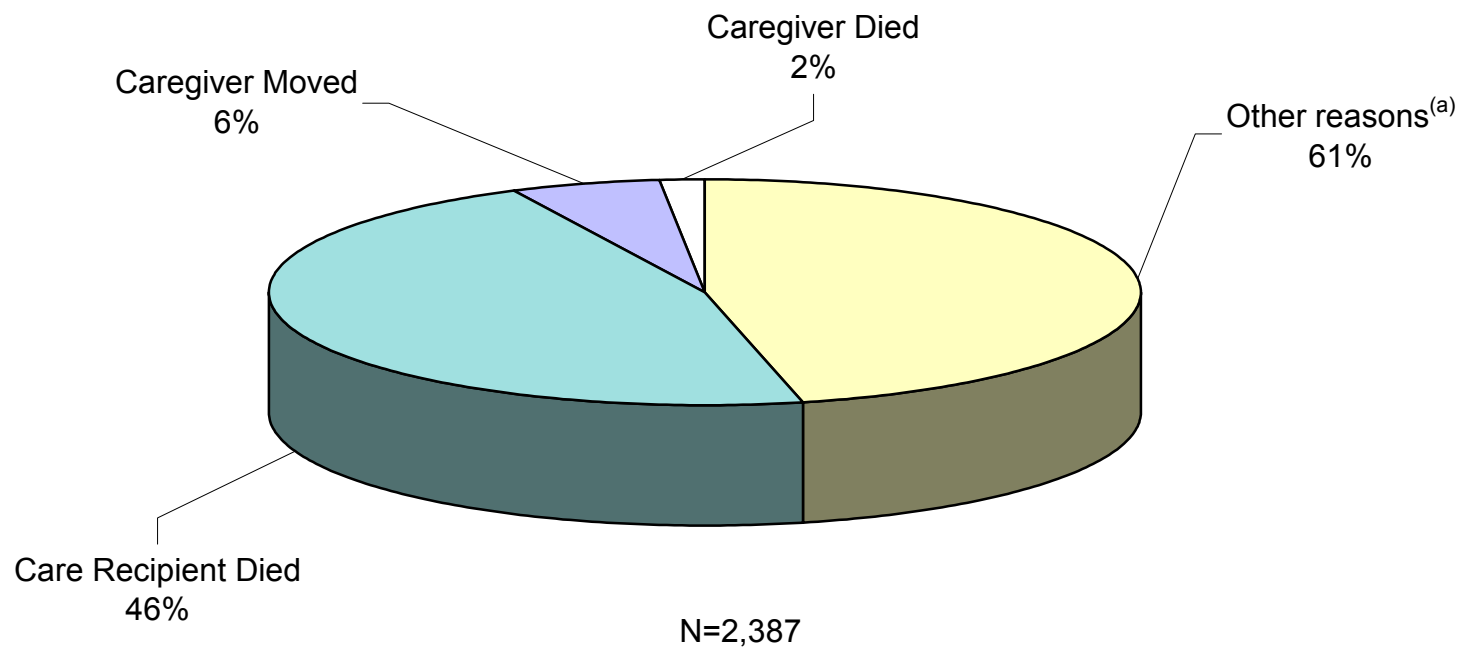


^a Based on 127,022 hours divided by 800 direct pay respite (in-home) clients.

^b Based on 64,201 hours divided by 752 vendor respite (in-home) clients.

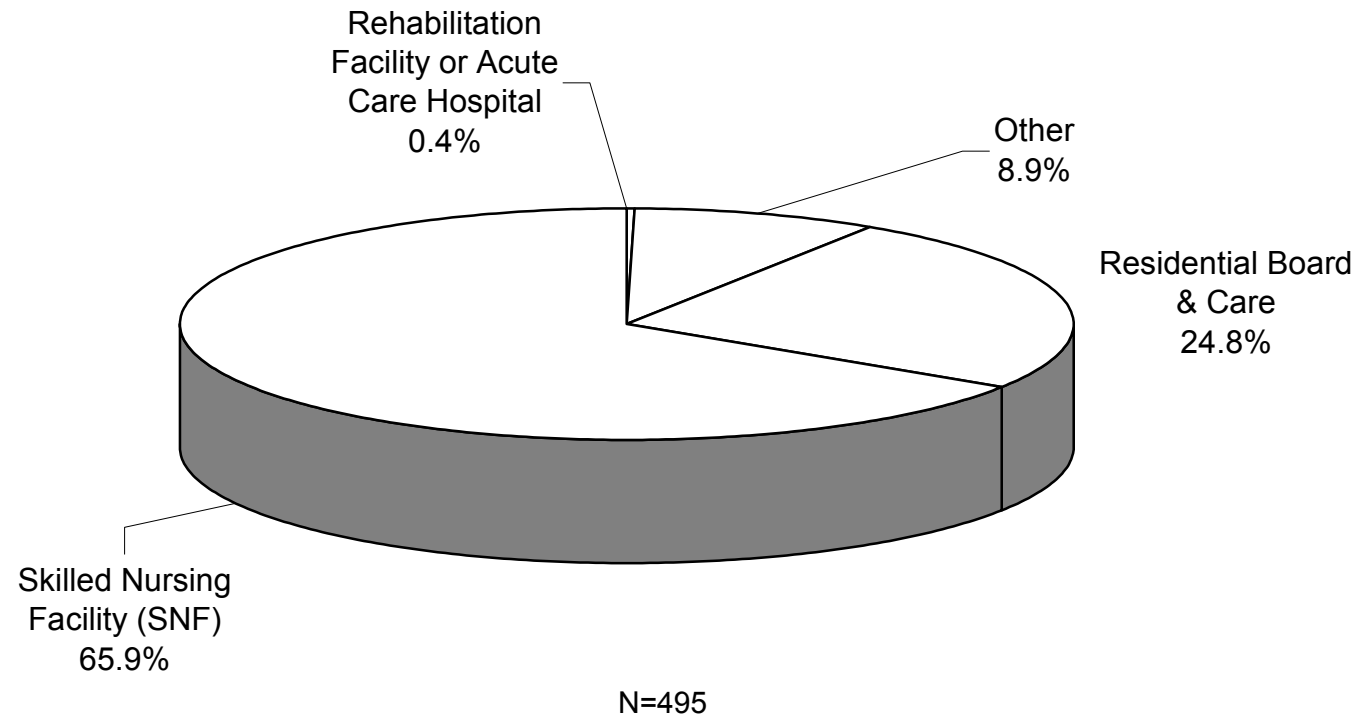
NOTE: Some families use more than one type of respite. Therefore, the sum of the clients using both direct pay and vendor respite may exceed the total number of clients receiving in-home respite.

FIGURE 9
CAREGIVER RESOURCE CENTERS
PERCENT OF CASES CLOSED BY REASON
FY 2001-2002



^a "Other Reasons" include families who declined further services or who could not be reached for a reassessment.

FIGURE 10
CAREGIVER RESOURCE CENTERS
PERCENT OF ADULTS WITH BRAIN IMPAIRMENT PLACED IN A
RESIDENTIAL FACILITY BY FACILITY TYPE
FY 2001-2002



CALIFORNIA'S CAREGIVER RESOURCE CENTERS SITE DISTRIBUTION LIST

Site Number, CRC, and Counties Served	Host Agency	Program Information
(01) BAY AREA CRC/FCA	Family Caregiver Alliance Kathleen Kelly Executive Director	Kathleen Kelly Bay Area Caregiver Resource Center
Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara	690 Market St., Suite 600 San Francisco, CA 94104 (415) 434-3388 (800) 445-8106 E-Mail: kkelly@caregiver.org	690 Market St., Suite 600 San Francisco, CA 94014 (415) 434-3388 (800) 445-8106 (statewide) FAX: (415) 434-3508 E-Mail: info@caregiver.org Web: www.caregiver.org
(02) REDWOOD CRC	North Coast Opportunities, Inc. Ernie Dickens Executive Director	Nancy Powers-Stone Program Director
Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, Sonoma	North Coast Opportunities, Inc. 43 North State Street Ukiah, CA 95482 (707) 462-1954 (800) 606-5550	Redwood Caregiver Resource Center 141 Stony Circle, Suite 200 Santa Rosa, CA 95401 (707) 542-0282 (800) 834-1636 (regional) FAX: (707) 542-0552 E-Mail: nps@redwoodcrc.org Web: www.redwoodcrc.org
(03) LOS ANGELES CRC	Andrus Gerontology Center Bob Knight, Ph.D. Faculty Liaison	Donna Benton, Ph.D. Director
Los Angeles	Leonard Davis School of Gerontology 3715 McClintock Avenue – MC 0191 Los Angeles, CA 90089-0191 (213) 740-5156	Los Angeles Caregiver Resource Center 3715 McClintock University Park, MC-0191 Los Angeles, CA 90089-0191 (213) 740-8711 (800) 540-4442 (regional) FAX: (213) 740-1871 E-Mail: benton@usc.edu Web: www.usc.edu.lacrc

Site Number, CRC, and Counties Served	Host Agency	Program Information
(04) INLAND CRC Inyo, Mono, Riverside, San Bernardino	Inland Caregiver Resource Center Robert Jabs, Ph.D. President 1420 E. Cooley Dr. Suite 100 Colton, CA 92324 (909) 514-1404	David Fraser Executive Director Inland Caregiver Resource Center 1420 E. Cooley Dr. Suite 100 Colton, CA 92324 (909) 514-1404 (800) 675-6694 (CA) FAX: (909) 514-1613 E-Mail: dfraser@inlandcaregivers.org
(05) DEL ORO CRC Colusa, Sutter, Yuba, Sierra, Nevada, Placer, El Dorado, Amador, Alpine, Calaveras, San Joaquin, Sacramento, Yolo	Del Oro Caregiver Resource Center Gerri Hopelain President 5723A Marconi Ave. Carmichael, CA 95608 (916) 971-0893	Janet E. Claypoole Executive Director Del Oro Caregiver Resource Center 5723A Marconi Avenue Carmichael, CA 95608 (916) 971-0893 (800) 635-0220 (regional) FAX: (916) 971-9446 E-Mail: jclaypoole@deloro.org Web: www.deloro.org
(06) SOUTHERN CRC San Diego, Imperial	Southern Caregiver Resource Center, Inc. Tom Reid, Esq. President 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432	Lorie Van Tilburg Executive Director Southern Caregiver Resource Center 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432 (800) 827-1008 (regional) FAX: (619) 268-7816 E-Mail: lvantilburg@caregivercenter.org Web: www.scrs.signonsandiego.com
(07) COAST CRC San Luis Obispo, Santa Barbara, Ventura	Rehabilitation Institute at Santa Barbara Scott Silic Vice President of Operations/CFO 5350 Hollister Ave. Suite C Santa Barbara, CA 93111 (805) 687-7444	John Gaynor Director Coast Caregiver Resource Center 5350 Hollister Avenue, Suite C Santa Barbara, CA 93111 (805) 967-0220 (800) 443-1236 (regional) FAX: (805) 967-5060 Email: jgaynor@coastcrc.org Web: www.coastcrc.org

Site Number, CRC, and Counties Served	Host Agency	Program Information
(08) MOUNTAIN CRC Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity	CSU Chico Research Foundation Jeanne Thomas, Ph.D. Chair, Center Policy Board California State University, Chico Chico, CA 95929-0450 (530) 898-6171	Vicki Farrell Program Director Mountain Caregiver Resource Center 2491 Carmichael Dr., Ste. 400 Chico, CA 95928 (530) 898-5925 (800) 822-0109 (regional) FAX (530) 898-4870 E-Mail: vfarrell@csuchico.edu Web: www.caregiverresources.org
(09) VALLEY CRC Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne	Valley Caregiver Resource Center Chris Morse President 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154	Margery Minney Executive Director Valley Caregiver Resource Center 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154 (800) 541-8614 (regional) FAX (559) 447-2143 E-Mail: mminney@valleycrc.org Web: www.valleycrc.org
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(11) ORANGE CRC Orange	Saint Jude Medical Center Barry Ross Vice President, Healthy Communities 101 East Valencia Mesa Drive Fullerton, CA 92835 (714) 992-3000	Claudia Ellano Program Director Orange Caregiver Resource Center 251 East Imperial Hwy., Suite 460 Fullerton, CA 92835-1020 (714) 578-8670 (800) 543-8312 (regional) FAX (714) 870-9708 E-Mail: cellano@sjf.stjoe.org Web: www.caregiveroc.org

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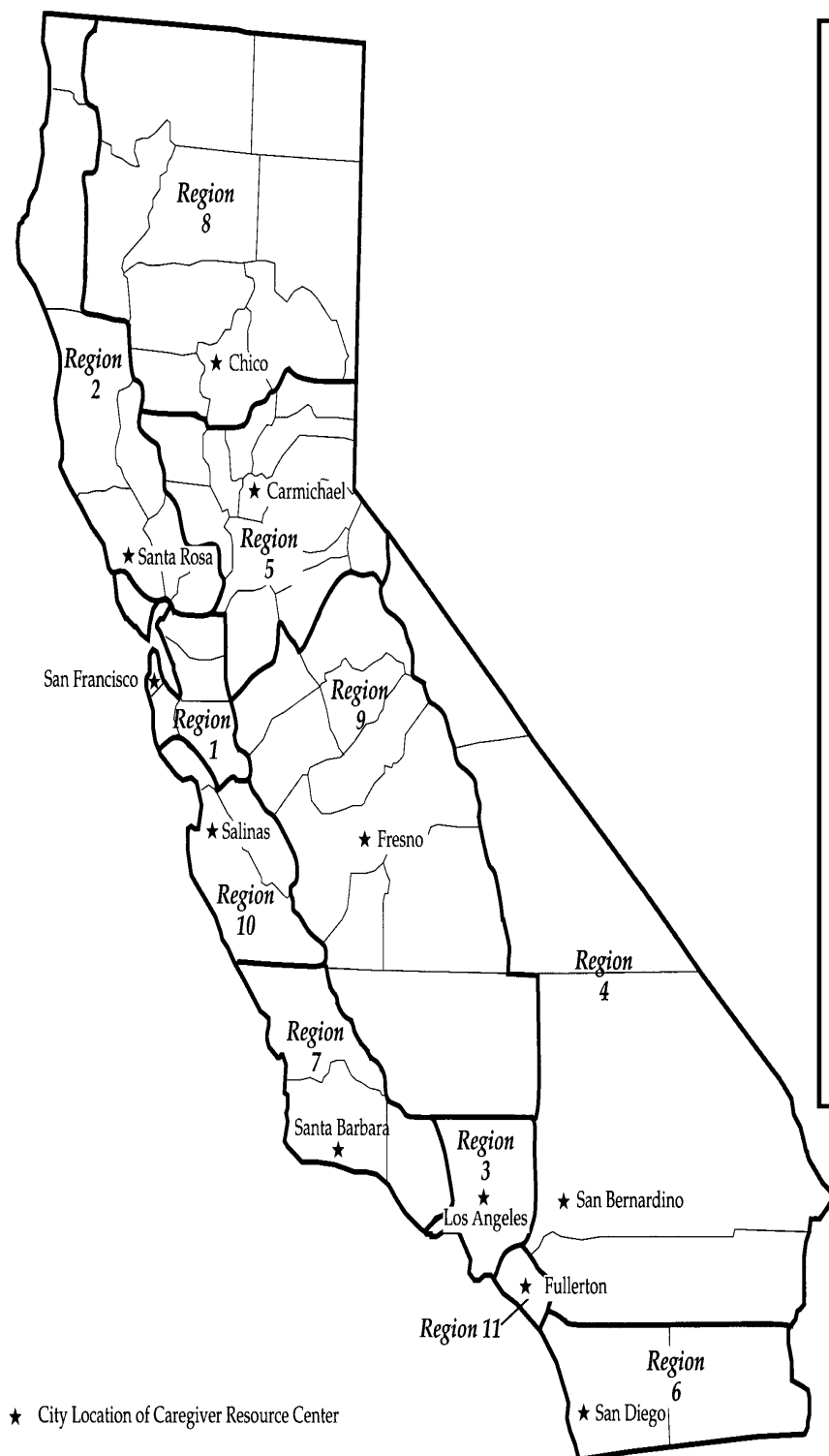
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MAP OF CALIFORNIA'S CAREGIVER RESOURCE CENTERS



★ City Location of Caregiver Resource Center

REGIONAL CAREGIVER RESOURCE CENTERS AND COUNTIES SERVED

- 1. Bay Area Caregiver Resource Center/Family Caregiver Alliance**
Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara
- 2. Redwood Caregiver Resource Center**
Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, Sonoma
- 3. Los Angeles Caregiver Resource Center**
Los Angeles
- 4. Inland Caregiver Resource Center**
Inyo, Mono, Riverside, San Bernardino
- 5. Del Oro Caregiver Resource Center**
Colusa, Sutter, Yuba, Sierra, Nevada, Placer, El Dorado, Amador, Alpine, Calaveras, San Joaquin, Sacramento, Yolo
- 6. Southern Caregiver Resource Center**
San Diego, Imperial
- 7. Coast Caregiver Resource Center**
San Luis Obispo, Santa Barbara, Ventura
- 8. Mountain Caregiver Resource Center**
Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity
- 9. Valley Caregiver Resource Center**
Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne
- 10. Del Mar Caregiver Resource Center**
Monterey, San Benito, Santa Cruz
- 11. Orange Caregiver Resource Center**
Orange

INCIDENCE AND PREVALENCE OF THE MAJOR CAUSES OF ADULT-ONSET COGNITIVE IMPAIRMENT IN THE UNITED STATES AND CALIFORNIA

Many of the diseases and disorders that affect the brain are progressive and their incidence and prevalence increase with age. Caring for those with adult on-set cognitive impairments frequently becomes a 24-hour, 7-days a week role. As the population ages, the need for care and for understanding the impact of these disorders on families is becoming even more pressing. A report released by the Federal Interagency Forum on Aging-Related Statistics,¹ states that 35.8% of those 85 or older have moderate or severe memory impairment. Persons 85 years and older are the fastest growing segment of California's population.² While the total population of California will double between 1990 and 2040, the population aged 85 and older will increase approximately 6-fold, from fewer than 300,000 to over 1.7 million.³

The loss of cognitive and functional abilities affects the individual and his or her family in profound ways. Caring for adults with cognitive impairments is often very stressful and demanding due to memory loss, behavioral and personality changes; chronic care needs and the high costs of care. Caregiving can span decades, can impact both the physical and mental health of the caregiver and can result in extreme economic hardship.

The following tables estimate the incidence and prevalence of the major causes of cognitive impairment in adulthood in the United States in general and in California in particular. The estimates are conservative, excluding rare disorders for which reliable data are not available.

- Table 1 shows an estimated 1.4 million people aged 18 years and older who are diagnosed annually with adult on-set cognitive disease/disorders in the United States (i.e. the incidence).
- Table 2 estimates that between 12.0 and 18.2 million individuals age 18 and over are afflicted with the more common cognitive disorders and diseases diagnosed (i.e. the number of people currently living with the impairment).
- Table 3 looks at the data in comparison to the overall population of the United States and California. An estimated 11% - 19% of the United States and California households may be dealing with the burden of caring for a loved one with an adult on-set cognitive disease/disorder.

Table 1: Incidence of Adult-Onset Brain Disorders⁴

DIAGNOSIS/CAUSE	PEOPLE DIAGNOSED ANNUALLY
Alzheimer's Disease	360,000 ⁵
Amyotrophic Lateral Sclerosis	5,000 ⁶
Brain Tumor	36,400 ⁷
Epilepsy	134,000 ⁸
HIV (AIDS) Dementia	1,196 ⁹
Huntington's Disease	N/A
Multiple Sclerosis	10,400 ¹⁰
Parkinson's Disease	50,000 ¹¹
Stroke	750,000 ¹²
Traumatic Brain Injury	85,000 ¹³
TOTAL ESTIMATED INCIDENCE	1,431,996

- With over 1.4 million adults diagnosed with a chronic cognitive disease or disorder in the United States annually, the need for both long-term care and support for family caregivers is dramatic. Many of these conditions, for example Alzheimer's disease, stroke, and Parkinson's disease, are associated with increasing age. Given the aging of the United States population, figures will increase proportionately in the coming decades.

Table 2: Prevalence of the Major Causes of Adult-Onset Brain Disorders

DIAGNOSIS/CAUSE	People Currently Living with the Disorder: Low Estimate	People Currently Living with the Disorder: High Estimate
Alzheimer's Disease	2,320,000 ¹⁴	4,000,000 ¹⁵
Amyotrophic Lateral Sclerosis	20,000 ¹⁶	30,000 ¹⁷
Brain Tumor	350,000 ¹⁸	350,000 ¹⁹
Epilepsy	1,984,000 ²⁰	2,000,000 ²¹
HIV Encephalopathy (dementia)	14,537 ²²	58,150 ²³
Huntington's Disease	30,000 ²⁴	30,000 ²⁵
Multiple Sclerosis	250,000 ²⁶	350,000 ²⁷
Parkinson's Disease	500,000 ²⁸	1,500,000 ²⁹
Stroke	4,000,000 ³⁰	4,600,000 ³¹
Traumatic Brain Injury	2,500,000 ³²	5,300,000 ³³
TOTAL PREVALENCE	11,986,537	18,218,150

- Table 2 dramatically illustrates the long-term nature of caregiving for many of these conditions. While it is estimated that 360,000 people are diagnosed with Alzheimer's annually in the United States, there are an estimated 2.32 million people living with the disease many of whom require 24-hour care.

Table 3: Select Population Characteristics: United States and California

	United States	California
Total Population	284,796,887 ³⁴	34,501,130 ³⁵
Total Population 18+	211,604,087 ³⁶	25,082,322 ³⁷
Total Households	105,480,101 ³⁸	11,502,870 ³⁹
Total Estimated Adults with Brain Impairment		
a. Low Estimate	11,968,537 ⁴⁰	1,418,681 ⁴¹
b. High Estimate	18,218,150 ⁴²	2,159,474 ⁴³
Percentage of Adult Population Affected by Brain Impairment		
a. Low Estimate	5.7%	5.7%
b. High Estimate	8.6%	8.6%
Percentage of Households Affected by Brain Impairment ⁴⁴		
a. Low Estimate	11.3%	12.3%
b. High Estimate	17.3%	18.8%

- The 17% figure for the number of households affected by cognitive impairment only begins to elucidate the impact of cognitive impairment upon family caregivers and the long-term care system. With many of these individuals requiring 24-hour care, there are often several family members from different households involved in the caregiving process including spouses, adult children, siblings and friends. Often these caregivers are juggling the responsibilities of caregiving, child rearing and employment simultaneously.

¹ Federal Interagency Forum on Aging-Related Statistics. (2000). *Older Americans 2000: Key indicators of well-being*. Retrieved November 1, 2002, from <http://www.agingstats.gov/chartbook2000/>

² California Department of Aging. (n.d.). *Quick facts: The elderly*. Retrieved October 23, 2002, from http://www.aging.state.ca.us/html/stats/map_narrative.htm

³ California Department of Aging. *The aging baby boomers: Influence on the growth of the oldest old*. Retrieved October 23, 2002, from http://www.aging.state.ca.us/html/stats/oldest_old_narrative.htm

⁴ Due to differences in reporting and data collection, estimates vary and in some cases the figures are for slightly different populations (e.g. aged 13+ or aged 15+) as noted.

⁵ Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *American Journal of Public Health*, 88, 1337-1342.

⁶ National Institute of Neurological Disorders and Stroke. (2000). Amyotrophic Lateral Sclerosis fact sheet. Retrieved October 22, 2002, from http://www.ninds.nih.gov/health_and_medical/pubs/als.htm

⁷ American Brain Tumor Association. (2002). *Facts and statistics*. Retrieved October 22, 2002, from <http://www.abta.org/primer/facts.htm> (Note: Persons diagnosed with a primary brain tumor.)

⁸ Epilepsy Foundation. (2000). *Cost study shows divide in treatment effect*. Retrieved October 17, 2002 from <http://www.efa.org/epusa/divide.html> (Note: Includes ages 15 and above.)

⁹ Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2): 18.

¹⁰ National Institute of Neurological Disorders and Stroke. (1996). *Multiple Sclerosis: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm

¹¹ American Parkinson's Disease Association. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>

¹² National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm

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- ¹³ Centers for Disease Control and Prevention. (1999). *Traumatic Brain Injury in the United States: A report to Congress*. Retrieved October 21, 2002 from <http://www.cdc.gov/ncipc/pub-res/tbicongress.htm> (Note: Estimate for the number of people who experience the onset of long-term disability due to a TBI.)
- ¹⁴ Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *American Journal of Public Health*, 88, 1337-1342.
- ¹⁵ Alzheimer's Disease and Related Disorders Association, Inc. (n.d.). *Statistics about Alzheimer's disease*. Retrieved November 5, 2002 from <http://www.alz.org/AboutAD/Statistics.htm>
- ¹⁶ National Institute of Neurological Disorders and Stroke. (2000). *Amyotrophic Lateral Sclerosis fact sheet*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/als.htm
- ¹⁷ Amyotrophic Lateral Sclerosis Association. (n.d.). *Quick facts about ALS and the ALSA*. Retrieved October 22, 2002 from <http://www.alsa.org/als/quickfacts.cfm>
- ¹⁸ American Brain Tumor Association. (2002). *Facts and statistics*. Retrieved October 22, 2002, from <http://www.abta.org/primer/facts.htm> (Note: Persons diagnosed with a primary brain tumor.)
- ¹⁹ Ibid.
- ²⁰ Epilepsy Foundation. (2000). *Cost study shows divide in treatment effect*. Retrieved October 17, 2002 from <http://www.epilepsy.org/epusa/divide.html> (Note: Includes ages 15 and above.)
- ²¹ National Institute of Neurological Disorders and Stroke. (2000). *Seizures and epilepsy: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/seizures_and_epilepsy_htr.htm
- ²² Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2). (Note: Estimated from 1997 data on the percent of individuals developing AIDS-Indicator conditions multiplied by the estimated number of adults/adolescents currently living with AIDS. Overall the CDC reports that the incidence of HIV dementia is decreasing.)
- ²³ Berghuis, J. P., Uldall, K. K. and Lalonde, B. (1999). Validity of two scales in identifying HIV-associated dementia. *Journal of Acquired Immune Deficiency Syndromes*, 21, pp. 134-140. (Note: Based on the high end of their estimate of 7-20% of HIV/AIDS patients developing dementia times the CDC estimate of individuals currently living with AIDS.)
- ²⁴ National Institute of Neurological Disorders and Stroke. (n.d.). *Huntington's disease: Hope through research*. Retrieved on October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/huntington_disease-htr.htm
- ²⁵ Ibid.
- ²⁶ National Institute of Neurological Disorders and Stroke. (1996). *Multiple Sclerosis: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm
- ²⁷ Ibid.
- ²⁸ National Institute of Neurological Disorders and Stroke. (n.d.). *Parkinson's disease: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/parkinson_disease_htr.htm
- ²⁹ National Parkinson Foundation. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>
- ³⁰ National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm
- ³¹ American Heart Association. (2002). *2002 heart and stroke statistical update*. Retrieved October 22, 2002 from <http://www.americanheart.org/statistics/>
- ³² National Institutes of Health. (1998). *Rehabilitation of persons with traumatic brain injury. NIH consensus statement online*. 1998 Oct 26-28. 16(1), 1-41. (Note: Estimate includes all ages.)
- ³³ Centers for Disease Control and Prevention. (n.d.). *Traumatic Brain Injury in the United States*. Retrieved October 21, 2002 from <http://www.cdc.gov/ncipc/didop/tbi.htm>
- ³⁴ U.S. Census Bureau. (1999). *Statistical Abstract of the United States: 1999*. Retrieved on October 22, 2002 from <http://quickfacts.census.gov/qfd/states/06000.html> (Note: Population figures for the U.S. and California are projections for the year 2000.)
- ³⁵ Ibid.
- ³⁶ Ibid.
- ³⁷ Ibid.
- ³⁸ Ibid.
- ³⁹ Ibid.
- ⁴⁰ See Table 2.
- ⁴¹ These estimates are based on the percentage of population age 18+ years residing in CA.
- ⁴² See Table 2.

⁴³ These estimates are based on the percentage of population age 18+ years residing in CA.

⁴⁴ Assumes one brain impaired individual per household.